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ABSTRACT

This report is based upon testimony submitted by mental health professionals; lawyers; advocates; people with psychiatric disabilities and their families at the National Council of Disability (NCD) hearing about the problems of those with psychiatric disabilities. Many reported of routine use and overuse of psychiatric drugs, often administered against a person's will. Such testimony pointed to the fact that people with psychiatric disabilities are systematically and routinely deprived of their rights and treated as less than full citizens or full human beings. Based on the testimony, the NCD concluded that the manner in which American society treats people with psychiatric problems constitutes a national emergency. Their recommendations all follow the same principle that people with psychiatric disabilities are first of all citizens who have the right to expect that they will be treated according to the principles of law that apply to all other citizens. Recommendations address the topics of forced drugging; individual rights; appropriate alternatives to care; availability of rehabilitation programs; and placement out of correctional institutions for juvenile offenders. Included are a glossary of terms and one appendix. (JDM)

ED 455 459

From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves

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From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

Letter of Transmittal

January 20, 2000

The President
The White House
Washington, DC 20500

Dear Mr. President:

I am pleased to submit the National Council on Disability's (NCD) report *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves*, which is based on the testimony of people with psychiatric disabilities who testified at an NCD hearing in 1998.

All the recommendations in this report emphasize the basic principle that people with psychiatric disabilities are, first and foremost, citizens who have the right to expect that they will be treated according to the principles of law that apply to all other citizens. All laws and policies that restrict the rights of people with psychiatric disabilities simply because of their disabilities are inharmonious with basic principles of law and justice, as well as with such landmark civil rights laws as the Americans with Disabilities Act.

We call on you, Mr. President and Congress, to address the problems described in this report, particularly by ensuring that people with psychiatric disabilities themselves are involved in a major way in making the policy changes that will enable them to claim their full citizenship rights.

We look forward to the day when the label of psychiatric disability has no more effect on people's rights than does the existence of any other disability label. Until that day, NCD believes that people with psychiatric disabilities will remain among the most underprivileged and disadvantaged of American citizens.

Sincerely,

Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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For many people, testifying and submitting testimony was an act of real courage. NCD recognizes and acknowledges this fact.

This report is based on their testimony.

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Executive Summary

The National Council on Disability (NCD) is an independent federal agency mandated to make recommendations to the President and Congress on disability issues. NCD generally does its work in a cross-disability manner, emphasizing that people with disabilities should be the ones who make the major decisions about their lives. NCD endorses and supports the principles of independent living, which has achieved the success it has because it is rooted in two unwavering principles: self-determination and consumer direction.

People with psychiatric disabilities are routinely deprived of their rights in a way no other disability group has been. In order to learn more about the problems of psychiatric disability, NCD conducted a hearing specifically on this topic. At the hearing, held in Albany, New York, in November 1998, NCD heard testimony from mental health professionals, lawyers, advocates, and relatives of people with psychiatric disabilities. However, unlike most investigations on the topic of psychiatric disability, the primary participants in this hearing were people with psychiatric disabilities themselves, who testified passionately and eloquently both about the mistreatment they had experienced or witnessed, and their proposals for real and viable change. NCD heard testimony graphically describing how people with psychiatric disabilities have been beaten, shocked, isolated, incarcerated, restricted, raped, deprived of food and bathroom privileges, and physically and psychologically abused in institutions and in their communities. The testimony pointed to the inescapable fact that people with psychiatric disabilities are systematically and routinely deprived of their rights, and treated as less than full citizens or full human beings.

> *Forced treatment and abuse aren't synonymous with healing. When persons are admitted in a general hospital for any other problems—stroke, cancer, broken hip, X rays, tests—these persons wouldn't dream of allowing the doctors, nurses, or nursing aides to lock them up, shock them up, tie them up, or drug them up, and the staff wouldn't do it to them. Those patients are treated with compassion, caring, respect, and dignity, and persons who have serious enough emotional/mental problems need to be treated the same.* (Bernice E. Loschen)

Finally, it is important to realize how cruelly this system preys on the worst fears and vulnerabilities of people in crisis. They isolate you from the rest of the world, and they become your only reference point. When they accuse someone of being treatment resistant, they are accusing them of not wanting to change their lives. I was told that this was the end of the line for me. If this didn't work, nothing would, and if I left, I would very likely kill myself. During the entire length of my treatment, they did nothing constructive for me, and they hurt me deeply. (Diana Rickard)

Joe Young of the New Jersey P&A testified about abuses he has witnessed in mental institutions.

Among the more egregious concerns: the administration of medication, often without consulting the resident, likely without informed consent, frequently with limited understanding of the likely effect on this particular individual, including possible long-term side effects, and often for reasons of control rather than treatment; the absence not just of regular effective treatment programs, but of any purposeful activity (residents can still be seen sleeping in hallways and in the dayroom when bedrooms are locked); the arbitrary (and often dangerous) application of restraints, seclusion, and isolation; and the continued warehousing of individuals for months, if not years, after the expiration of any determination of [danger]. (Joe Young)

Diana Rickard testified about the degrading extent of the denial of basic human rights while she was institutionalized.

The unit structure is based on privileges and punishments, which are referred to as consequences, since they maintain these are not punitive. [The structure] will not allow any kind of privacy whatsoever, and everything is a potential treatment issue, including nail-biting and not making one's bed. They maintain control through humiliation and fear of humiliation. (Diana Rickard)

NCD heard many reports of the routine use and overuse of psychiatric drugs, often against people's will.

> *When I was in a psychiatric facility, because I questioned conditions, I was dragged into solitary confinement and held down on a bare mattress, forcibly injected with powerful psychiatric drugs, and held in solitary confinement. And I found since then that this is routine, that this is happening all over the—all over the psychiatric system. Usually forced psychiatric drugging occurs behind institutional walls, but in the last few years coerced drugging is now out in the community. Thirty-six U.S. states and the District of Columbia have involuntary outpatient commitment laws, which allow people to be court ordered to take their psychiatric drugs against their expressed wishes, even if they're living at home.* (David Oaks)

> *Even though most people with psychiatric disabilities are capable of participating in the decisions affecting their own care, they are often subjected to forced treatment. Given appropriate supports and full protection of their civil rights, the great majority of people with psychiatric disabilities are quite able not only to participate in their own health care but to become fully productive and creative members of mainstream society. But those simple supports and protections are rarely provided. Millions of people with psychiatric disabilities exist as virtual outcasts. This massive discrimination costs our nation uncounted billions of dollars in obsolete services and lost productivity. More important, in the land of liberty and justice for all, it is morally intolerable.* (Justin Dart, April 20, 1999)

Based on the testimony it received, NCD has concluded that the manner in which American society treats people with psychiatric disabilities constitutes a national emergency and a national disgrace. Because people with psychiatric disabilities are routinely deprived of their most fundamental rights, NCD believes that drastic change is necessary in a number of systems that deal with this population. Changes must be made not only in the mental health system, but in the criminal and civil justice systems, housing, income supports, education, job training, and

many others, so that people with psychiatric disabilities are guaranteed their fundamental rights as American citizens.

NCD has also concluded that one of the reasons public policy concerning psychiatric disability is so different from that concerning other disabilities is the systematic exclusion of people with psychiatric disabilities from policymaking. It is rare that people with psychiatric disabilities are heard in public-policy forums, and when they are, it is usually in token numbers. NCD's hearing was unique because it focused its attention on the direct experiences of people with psychiatric disabilities themselves and their calls for fundamental change.

The foremost change that is needed, as referred to by speaker after speaker, is the elimination of coercion from the provision of mental health services. Involuntary commitment and forced treatment, which often go unquestioned in discussions of mental health policy, were described again and again as being among the most painful and difficult experiences of people's lives. In addition, coercion was repeatedly noted as being a barrier to seeking out voluntary treatment, since people knew that once they entered the treatment system they could be coerced or involuntarily committed at any point. At a time when American citizens are being urged to do away with the stigma of mental illness and to voluntarily seek treatment for emotional difficulties, it becomes particularly important to ensure that people are able to do so without surrendering their fundamental rights.

Therefore, NCD recommends that the use of involuntary treatments, such as forced drugging and inpatient and outpatient commitment laws, should be viewed as inherently suspect and as incompatible with the principles of self-determination. Public policy should be directed toward establishing a totally voluntary mental health system.

NCD also recommends that aversive treatments, which involve the infliction of pain or the restriction of movement for purposes of changing behavior, should be banned, since they are also incompatible with self-determination principles. Practices that would often be illegal if administered to people without disabilities are routinely used on people with psychiatric disabilities in the name of "treatment." Such practices should shock the consciences of all Americans.

All of the recommendations in NCD's report follow the same basic principles: that people with psychiatric disabilities are, first and foremost, citizens who have the right to expect that they will be treated according to the principles of law that apply to all other citizens. All laws and policies that restrict the rights of people with psychiatric disabilities solely because of their disabilities are at odds with basic principles of law and justice, as well as with such landmark civil rights laws as the Americans with Disabilities Act (ADA).

NCD calls on the President and Congress to address the problems described in its report, particularly by ensuring that people with psychiatric disabilities themselves are involved in a major way in making the policy changes that will enable them to claim their full citizenship rights. NCD also calls on the media to address the problems described herein, and to avoid the negative stereotyping that has often typified public discussions of mental illness.

NCD looks forward to the day when the label of psychiatric disability has no more effect on people's rights than does any other disability label. Until that day, NCD believes that people with psychiatric disabilities will remain among the most underprivileged and disadvantaged of American citizens.

The recommendations that follow center on the importance of self-determination, dignity, and choice as the cornerstone of public policy for people in this highly disempowered population. As Congress stated when it passed ADA, disability is a natural part of the human experience that in no way should limit the ability of people to make choices, pursue meaningful careers, live independently, and participate fully in all aspects of American society. NCD believes that these recommendations, if implemented, would help to ensure that the public policy goals articulated in ADA become a reality for people labeled with psychiatric disabilities in the United States.

Core Recommendations

Therefore, NCD has developed 10 core recommendations in this report. These policy recommendations should be viewed from the context of the larger report, which follows. These deeply held core beliefs form, however, a dynamic backdrop to highlight the human and civil rights of people who have experienced the mental health system, people who should be viewed

as the true experts on their experiences, beliefs, and values, which should be used as a guiding force for changing public policy related to these issues in America.

1. Laws that allow the use of involuntary treatments such as forced drugging and inpatient and outpatient commitment should be viewed as inherently suspect, because they are incompatible with the principle of self-determination. Public policy needs to move in the direction of a totally voluntary community-based mental health system that safeguards human dignity and respects individual autonomy.

2. People labeled with psychiatric disabilities should have a major role in the direction and control of programs and services designed for their benefit. This central role must be played by people labeled with psychiatric disabilities themselves, and should not be confused with the roles that family members, professional advocates, and others often play when "consumer" input is sought.

3. Mental health treatment should be about healing, not punishment. Accordingly, the use of aversive treatments, including physical and chemical restraints, seclusion, and similar techniques that restrict freedom of movement, should be banned. Also, public policy should move toward the elimination of electro-convulsive therapy and psycho surgery as unproven and inherently inhumane procedures. Effective humane alternatives to these techniques exist now and should be promoted.

4. Federal research and demonstration resources should place a higher priority on the development of culturally appropriate alternatives to the medical and biochemical approaches to treatment of people labeled with psychiatric disabilities, including self-help, peer support, and other consumer/survivor-driven alternatives to the traditional mental health system.

5. Eligibility for services in the community should never be contingent on participation in treatment programs. People labeled with psychiatric disabilities should be able to select from a menu of independently available services and programs, including mental health services, housing, vocational training, and job placement, and should be free to reject any

service or program. Moreover, in part in response to the Supreme Court's decision in *Olmstead v. L C.*, State and federal governments should work with people labeled with psychiatric disabilities and others receiving publicly-funded care in institutions to expand culturally appropriate home- and community-based supports so that people are able to leave institutional care and, if they choose, access an effective, flexible, consumer/survivor-driven system of supports and services in the community.

6. Employment and training and vocational rehabilitation programs must account for the wide range of abilities, skills, knowledge, and experience of people labeled with psychiatric disabilities by administering programs that are highly individualized and responsive to the abilities, preferences, and personal goals of program participants.

7. Federal income support programs like Supplemental Security Income and Social Security Disability Insurance should provide flexible and work-friendly support options so that people with episodic or unpredictable disabilities are not required to participate in the current "all or nothing" federal disability benefit system, often at the expense of pursuing their employment goals.

8. To assure that parity laws do not make it easier to force people into accepting "treatments" they do not want, it is critical that these laws define parity only in terms of voluntary treatments and services.

9. Government civil rights enforcement agencies and publicly-funded advocacy organizations should work more closely together and with adequate funding to implement effectively critical existing laws like the Americans with Disabilities Act, Fair Housing Act, Civil Rights of Institutionalized Persons Act, Protection and Advocacy for Individuals with Mental Illness Act, and Individuals with Disabilities Education Act, giving people labeled with psychiatric disabilities a central role in setting the priorities for enforcement and implementation of these laws.

10. Federal, state, and local governments, including education, health care, social services, juvenile justice, and civil rights enforcement agencies, must work together to reduce the

placement of children and young adults with disabilities, particularly those labeled seriously emotionally disturbed, in correctional facilities and other segregated settings. These placements are often harmful, inconsistent with the federally-protected right to a free and appropriate public education, and unnecessary if timely, coordinated, family-centered supports and services are made available in mainstream settings.

Chapter 1

When Helping Hurts

The independent living movement for people with physical disabilities in the United States and abroad has achieved the success it has because it is rooted in two unwavering principles: self-determination and consumer direction. This great civil rights movement has challenged the old assumptions of the medical model—dependency and incompetence—that were used to justify exclusion. The independent living movement requires that people with disabilities must have maximum control of their lives.

An indispensable element of self-determination is the concept of consumer direction. Since people with disabilities are the experts on which social priorities hinder or enhance their own progress, the disability rights movement advocates that people with disabilities should control the organizations that serve and/or represent them. To ensure complete autonomy over their lives, people with disabilities should have ultimate control in allocating resources that support their independence.

The independent living movement has also challenged the role of the medical profession in controlling the lives of people with disabilities. For too long, medical professionals have assumed the right to make decisions for people with disabilities that go far beyond questions of medical treatment. People with disabilities have demanded that they be partners with medical professionals concerning their medical care, and that doctors and others should not be involved in deciding nonmedical aspects of their lives, such as where and how they live or work.

In addition to medical professions, many other individuals and groups have claimed the right to make decisions on behalf of people with disabilities. Family members, educators, legislators, and members of various helping professions have been among the groups that claimed they knew what people with disabilities wanted and needed. The growth of the independent living movement is based on the overriding concept that it is people with disabilities themselves who must make the decisions about how to live, just as other citizens do.

The wisdom of the philosophy of consumer control is now so widely accepted that federal funding of independent living centers is tied to the requirement that their decision-making boards be composed of a majority of people with disabilities. However, even with the significant strides the independent living movement has made, people with disabilities still do not control most of the organizations that provide services to them.

Our nation has declared with resounding statements, particularly the Americans with Disabilities Act (ADA), that the humanity of people with disabilities is to be respected and defended and that they, like all Americans, deserve the freedom and support to go as far as their desires and abilities will take them. Sádly, our nation has forsaken such ideals for people with psychiatric disabilities. The disability rights and independent living movements have in most cases failed to defend with equal passion the rights and humanity of people with psychiatric disabilities. While discrimination and abuse toward people with physical disabilities stirs indignation, at the same time we barely notice that people with psychiatric disabilities endure both on a daily basis. Unfortunately, like most Americans, the disability rights and independent living movements are still too quick to accept powerful demonizing stereotypes that people with psychiatric disabilities are crazy, dangerous, stupid, and evil. Recognizing and eliminating these prejudices will empower people with psychiatric disabilities to achieve the same self-determination now available to many of their peers with physical disabilities, and to build a strong, unified cross-disability movement.

Misconceptions about dangerousness are among the justifications that allow the maltreatment and abuse of people with psychiatric disabilities. With the exception of people with psychiatric disabilities themselves, few people question such routine practices as involuntary commitment, forced drugging, segregation both in institutions and community programs, and the routine use of restraint and seclusion. In order to learn more about the problems of psychiatric disability, the National Council on Disability (NCD) conducted a hearing specifically on this topic. At the hearing, held in Albany, New York, in November 1998, NCD heard testimony from mental health professionals, lawyers, advocates, and relatives of people with psychiatric disabilities. However, unlike most investigations on the topic of psychiatric disability, the primary participants in this hearing were people with psychiatric disabilities

themselves, who testified passionately and eloquently both about the mistreatment they had experienced or witnessed, and their proposals for real and viable change. NCD heard testimony graphically describing how people with psychiatric disabilities have been beaten, shocked, isolated, incarcerated, restricted, raped, deprived of access to food and bathroom facilities, and physically and psychologically abused in institutions and in their communities. The testimony pointed to the inescapable fact that people with psychiatric disabilities are systematically and routinely deprived of their rights and treated as less than full citizens or full human beings.

People with psychiatric disabilities are the only Americans who can have their freedom taken away and be institutionalized or incarcerated without being convicted of a crime and with minimal or no respect for their due process rights. They are the only Americans who can routinely be forced to submit to medical treatments against their will. When people with psychiatric disabilities die in facilities that are supposed to serve and protect them, their deaths are rarely investigated, and even when they are, criminal charges are rarely filed. This not happening in some Third World country. This is happening every day in the United States, and such practices are generally ignored or defended by mental health professionals, political leadership, and the media.

Involuntary treatment is extremely rare outside the psychiatric system, allowable only in such cases as unconsciousness or the inability to communicate. People with psychiatric disabilities, on the other hand, even when they vigorously protest treatments they do not want, are routinely subjected to them anyway, on the justification that they "lack insight" or are unable to recognize their need for treatment because of their "mental illness." In practice, "lack of insight" becomes disagreement with the treating professional, and people who disagree are labeled "noncompliant" or "uncooperative with treatment." After years of contact with a system that routinely does not recognize their preferences or desires, many people with psychiatric disabilities become resigned to their fate and cease to protest openly. Although this is described in the psychiatric literature as "compliance," it is actually learned helplessness (also known as "internalized oppression") that is incompatible with hope and with the possibility of recovery.

Traditionally, involuntary commitment has involved the loss of liberty and confinement in a facility. However, more recently the concept of involuntary outpatient commitment (IOC) has become more widespread. IOC laws have been passed in nearly two-thirds of the states, and similar legislation has been introduced in Congress. IOC involves court-ordered treatment (almost always medication) for people who do not meet the standards for inpatient commitment (physical dangerousness to self or others). With more states enacting IOC laws, more people with psychiatric disabilities are being forced to take medications and treatments that can be painful and debilitating. At the same time, the desire of many people labeled with psychiatric disabilities for voluntary services that affect their real-life needs (such as housing, job training, and social support) seldom receive adequate funding. One of the consequences of IOC laws is that they often take money from voluntary programs that promote independence and redirect it toward ever more restrictive and punitive programs.

Antiquated public policy priorities based on the medical model play key roles in perpetuating these injustices. These policies have been shaped without any meaningful participation by people labeled with psychiatric disabilities. America must listen to the eloquent voices of people who live with psychiatric disabilities, and accept them as the real experts who can create humane and empowering public policies dedicated to the ideals of independent living—self-determination and consumer direction.

> *We are locked up without due process and without knowing how long our sentence will be....We become physically disabled by the so-called treatments we are given, such as brain-damaging electroshock and psychiatric drugs. We are the scapegoats of the society....If people can say it is our fault and we are the defective ones, then they don't have to face the issues that are happening in society that are oppressing people.* (Janet Foner)

Americans with disabilities commonly confront violations of their civil rights. But the deeply entrenched prejudice, violence, and maltreatment perpetrated against people labeled with psychiatric disabilities extend beyond the realm of civil rights. Again and again, NCD heard

moving and powerful testimony describing the deprivation of basic human rights in the name of treatment.

> *I spent 15 consecutive months on Unit 5 North. This was the single most traumatic experience of my life. The treatment consisted of an unrelenting, 24-hour-a-day attack on my personal autonomy and self-esteem, which I believe only exacerbated my symptoms.* (Diana Rickard)

PAIMI's Challenge

Anyone with a psychiatric disability, in fact anyone deemed by a mental health professional or police officer with little or no training to have such a disability, can be legally deprived of their freedom simply with an order from a judge, law officer, or medical professional. The due process procedures to challenge those decisions, and the laws and agencies that are supposed to protect and defend the legal rights of people affected by such orders, are often inadequate, ineffective, underfunded, inaccessible, or disregarded. Even when people are entitled to hearings, these are usually brief, and representation by counsel is often inadequate or nonexistent. The Protection and Advocacy for Individuals with Mental Illness (PAIMI) program of the federally funded Protection and Advocacy (P&A) system is underfunded and inadequate because of statutory limitations to protect people labeled with psychiatric disabilities from abuse and neglect. Further, the PAIMI program itself, in common with other elements of the services system for people labeled with psychiatric disabilities, has little input from the people it is supposed to serve, nor do many agencies reach out to people in recovery to seek their input.

Once the system fails them and they are defined as "mentally ill," people labeled with psychiatric disabilities are isolated from and ignored by society. Joe Young, a legal advocate from New Jersey Protection and Advocacy, testified on the conditions he has observed in institutions:

During the four years that NJP&A has sought to monitor the conditions in the state-run psychiatric hospitals, we have witnessed distressing, but I am certain not unusual, conditions that few, if any, of us would subject ourselves to voluntarily.

Such conditions are not unique to New Jersey. When Marc Keifer entered East Bay Hospital in Richmond, California, on the evening of February 1, 1993, he was a physically healthy 38-year-old man. Less than two days later, Keifer, who carried a diagnosis of paranoid schizophrenia, died alone in an isolation room after he was restrained to a bed with leather straps, belts, and cuffs for 18 hours. A protection and advocacy investigation determined that Keifer likely died from "the undiagnosed and untreated medical condition of anticholinergic toxicity from psychiatric medications, as well as a prolonged period of improperly monitored seclusion and restraint." Such deaths are, unfortunately, not rare.

Because protection and advocacy agencies lack adequate funding and resources, many people are left helpless and defenseless, as the public affairs manager of a California protection and advocacy agency testified:

I am very sad to say that this [investigational] unit is always extremely busy and cannot keep up with all the requests we receive to investigate individual cases of abuse and neglect of people with disabilities in California hospitals and institutions. (Stacie Hiramoto)

P&As responded to 34,000 complaints regarding abuse and neglect in 1998, and have conducted 5,000 death investigations over the past 20 years. Cases that come to the attention of P&As represent merely the tip of the iceberg. The *American Journal of Psychiatry* reported that as many as 81 percent of women with psychiatric disabilities have been physically or sexually abused in institutions. In the general population, some 1,000 rapes occur each day, but only 300 of them are reported, according to the U.S. Office of Victims Assistance at the U.S. Department of Justice (DOJ). Likewise, the numbers of abuse and neglect complaints P&As responded to may be vastly understated as the majority of these incidents perpetrated against people with disabilities also are never reported.

Based on my 20 years of work with the Commission, I believe too many consumer complaints or suspicions of abuse are buried with the body. (Thomas R. Harmon, director of medical review and investigations, New York State Commission on Quality of Care)

An attorney testified that the statutory eligibility criteria for PAIMI services are too narrowly drawn. (PAIMI services are available to people labeled with psychiatric disabilities who are in institutions; or in the process of being admitted to or transported to one; or who are in a detention facility, jail, or prison; or with respect to matters that took place within 90 days of discharge from such facilities.) Since 1986, when the PAIMI law was enacted, there have been profound changes in the mental health delivery system that are not reflected in existing legislation. Nowadays, when many people labeled with psychiatric disabilities are subjected to outpatient programs that severely curtain their rights, the PAIMI's statutory limitations leave these people without the availability of legal advocacy. Several years ago, funding of legal services programs for low-income people, including people with disabilities, was severely restricted. People testifying indicated concern that P&A organizations will be similarly cut.

I wanted to urge you to advocate to preserve that system, to expand the system, and also to ensure that it does not fall prey to the kind of destructive limitations...that have happened to the federal legal services program. Those sorts of restrictions, if placed on the P&A system, would absolutely devastate the effectiveness. (Cliff Zucker)

Merely increasing the funding for PAIMI programs is not enough. Vigorous efforts must be made to ensure that PAIMIs are responsive to the people they serve. Current federal law requires that people labeled with psychiatric disabilities or their relatives be a majority on PAIMI advisory councils, but there is no similar requirement for their governing boards. While some advisory councils are heavily involved in oversight of the PAIMI program, others have minimal roles and may serve as a mere rubber stamp.

Further, there is an inherent conflict of interest in having federal oversight of the PAIMI program located in the Center for Mental Health Services (CMHS), which is an organization

primarily concerned with service delivery and not with legal or rights issues. It would make far more sense to locate federal oversight of PAIMI programs in the Office of Civil Rights of the Department of Health and Human Services, or in the Department of Justice.

Even under the watchful eye of DOJ, people die from abuse and neglect in institutions. Since 1990, DOJ has been scrutinizing Virginia's state mental hospital system, which encompasses 15 facilities that house some 3,800 people. In 1994, after the deaths of three people in one year at the Northern Virginia Mental Health Institute, DOJ initiated an investigation, and in 1996 sued the Institute and two other Virginia facilities because of inadequate care. In 1997, DOJ reached a settlement with the Institute after it agreed to make the required improvements. But in 1998, two more people died. John N. Follansbee, the former medical director of the facility, reported in the June 12, 1999, edition of *The Washington Post* that the facility is not likely to meet the improvement goals set by DOJ.

The Fall 1997 issue of a Sacramento, California, P&A newsletter reports that a woman died at the Butte County Inpatient Psychiatric Health Facility when she suffered third-degree burns over 80 percent of her body while showering with hot water. Although California regulations covered hot water temperatures in other health facilities, they did not cover the water temperature in psychiatric hospitals. This is just one more example of how people labeled with psychiatric disabilities are denied equal protection of law.

An advocate from the New York State Commission for Quality of Care testified that:

> *Each year the commission receives, reviews, and, where necessary, directly investigates about 7,000 reports of abuse and over 2,000 reports of consumer deaths....We have investigated over 200 deaths where restraint or seclusion was a factor....In our casework, we've seen people die or be abused in restraint because a simple request for a second cup of coffee was denied; or a request for a sweater on a very cold day was ignored by staff.* (Thomas R. Harmon)

One sexual abuse survivor, who was forcibly restrained while in a mental institution, continues to relive the horror through nightmares. In her testimony about the traumatizing incident, she stated:

> *Eight men jumped on top of me and wrestled me to the floor. They held me face-down on the floor, restrained me, and then shot me up [with] Thorazine. I then waited in restraints for hours until they thought my behavior was appropriate to be released. I remember begging with them like a dog to release me. I was totally powerless and at their mercy.* (Marcie Kelley)

For someone who has survived sexual abuse or who is a victim of rape, restraints are especially abusive and traumatizing. However, many mental health professionals may not recognize this danger. *Victim Empowerment: Bridging the Systems—Mental Health and Victim Service Providers*, a resource manual produced with a grant from DOJ's Office for Victims of Crime, reports that, historically, mental health counselors, psychologists, and psychiatrists have not received extensive training in victimization issues. At the Erie County Rape Crisis Center in Pennsylvania, for example, approximately 25 percent of clients who were victims of sexual assault/abuse or other crimes were also receiving services at one or more mental health programs.

A 1997 report by the California P&A describes a pattern of improper seclusion and restraint use from 1994 to 1996 at Napa State Hospital (NSH), one of four state hospitals operated by the California Department of Mental Health. Incidents included:

- the death of a deaf man with a physical disability who was improperly restrained in a chair;
- the unlawful restraint of two children with hearing impairments in their beds; and
- the seclusion of a child with a hearing impairment in a closet full of soiled linens.

For more than a year and a half, one unit at the hospital repeatedly secluded patients. When the abuse was finally reported by a staff member, the shift leader successfully encouraged other staff to engage in a cover-up, and to lie to management and Napa State Hospital's (NSH's)

senior special investigator during the institution's initial internal investigation. P&A investigators also determined that the facility's primary law enforcement officer responsible for investigating the alleged abuse failed to conduct a minimally adequate investigation into the seclusion practices on the unit. The report concluded that both felonies and misdemeanors, including assault, battery, false imprisonment, criminal conspiracy, child endangerment, and corporal punishment of a child may have been committed by NSH employees. But no criminal charges were filed.

Testimony also revealed that the quality of mental and medical services available to people labeled with psychiatric disabilities is questionable. In fact, many consumers complained that the most commonly offered treatments, such as powerful medications with adverse side effects, actually deter and frighten people labeled with psychiatric disabilities away from seeking treatment.

> *The so-called side effects of many psychiatric drugs are far more noticeable than the so-called main effects. And these drugs have the potential to cause serious physical illness and even death. So, it's very logical that many people would refuse them.* (Judi Chamberlin)

> *I just want to mention a few of the real hazards of psychiatric drugging. The neuroleptics like Thorazine, Haldol, Mellaril, Navane—all those I was on—and now there's also Closapine and Resperdal. All of these drugs can sometimes kill. Now, a lot of our members choose to take these drugs of their own will, and that's their choice. But coercion and force are just plain wrong. In the long run, psychiatric drugs can cause persistent brain changes, making it very, very difficult to withdraw. With the neuroleptics, it peaks at three months after quitting, you can feel crazier, so-called, than you did before you started. This is a brain disability caused by the drug, keeping these people on for life.* (David Oaks)

Many of the prescription drugs used in treatment programs do have devastating side effects. Particularly in programs that treat people by force, there are few, if any, opportunities for informed consent, discussion of alternatives, or the right to refuse treatment.

Because of the number of adverse drug experiences received from health professionals and consumers, Zoloft, a frequently prescribed antidepressant, is listed as one of the top 10 ranked suspect drugs in the FDA's *1996 Adverse Drug Experience Report*. And Zoloft is only one of a multitude of drugs, all with their own sets of side effects, commonly prescribed to people labeled with psychiatric disabilities.

Much of the testimony concerned people's experiences in institutions with "treatments" that involve the administering of powerful psychiatric medications, electroconvulsive therapy, restraints, calming blankets, and isolation that were administered by their "caregivers." The fact that so many people came forward to talk about these experiences is one more indication of the ways in which such information has been excluded from the development of public policy, because NCD, unlike many other forums, specifically encouraged testimony by people labeled with psychiatric disabilities themselves.

Mental health service provider Marcie Kelley has personally experienced the adverse effects of restraints.

> *As a survivor of sexual abuse, I personally have found the use of restraints on me more traumatizing than being sexually abused. Being put in restraints is a much longer, traumatic ordeal than being raped.* (Marcie Kelley)

In 1997 the *Journal of the American Geriatric Society* reported that physical restraints used on humans cause severe stress, high rates of serious accidents—including death by asphyxiation—functional decline, psychological distress, increased agitation, circulation impairment, skin breakdown, increased incontinence, decreased mobility, and even irreversible brain damage in postmenopausal women with low estrogen levels. Yet such methods continue to be used in programs for people with disabilities and are defended by many professionals as legitimate treatments. Susan Stefan, J.D., a professor of law at the University of Florida, has conducted extensive research among people with psychiatric disabilities.

> *I have interviewed many, many people with psychiatric disabilities, and sent a survey to thousands of people, literally, and received hundreds of surveys back, and what*

the surveys are saying and what the interviews are saying are that people are dying, being injured, and sexually assaulted in institutions. They're being ignored and overmedicated. They're dying and being damaged in restraints. When I tried to relate the individual stories that I was getting to the research and data out in the field, what I discovered is that there is no research, or that it is terribly, terribly difficult to put together, or that it is virtually useless. The voices of people with psychiatric disabilities are silenced. Their stories are dismissed as anecdotal, because of choices we [researchers] make about what information must be gathered and what information may be systematically ignored. (Susan Stefan, J.D.)

Professor Stefan testified that restraints are a crutch for understaffed units and untrained staff, and referred to one study that attributed the near absence of violence on a psychiatric unit to never using restraint or seclusion. She also stated that it is difficult to determine the cause of death and the number of people who die in psychiatric institutions and other psychiatric residential settings because coroners' reports—except for obvious suicides—typically list the cause of death as cardiac arrest, which is questionable since many of the people who die are relatively young and have no previous history of cardiac problems.

In 1994, a 47-year-old grandmother of four was placed face-down in five-point restraints at John George Psychiatric Pavilion in San Leandro, California. Despite her claims that she could not breathe, she remained restrained face-down. Staff left her unattended and locked the door of the seclusion room. When staff returned ten minutes later, she was unresponsive and not breathing. Efforts to resuscitate her failed. The coroner determined that the cause of death was suffocation from being restrained face-down. This was the eighth seclusion or restraint death that the P&A had investigated in three years.

Restraints seemed to be overutilized when psychiatric hospitals are understaffed and do not have time to deal with crisis situations in a civilized manner. I urge the federal government to put stricter regulations in place for the use of restraints, to investigate this form of what I consider to be torture...and to hold hospitals accountable for the murders they commit when using restraints. (Marcie Kelley)

Kelley also commented on *Deadly Restraints*, a series of articles published in *The Hartford Courant* from October 10–15, 1998, investigating the illegal use of restraints and other aversive therapies.

> *Recent reports by the* Courant *indicate that between 50 and 150 deaths occur every year across the country due to patients being restrained. This statistic is drastically underestimated, since many deaths from restraints go unreported or are covered up by hospital staff.* (Marcie Kelley)

Unfortunately, medical examiners rarely connect the circumstances of a death to restraints illegally used by hospital staff, which further complicates investigation and prosecution. As a result of the *Courant*'s series, Congress held hearings and legislation was introduced on the use of restraints. The Health Care Financing Administration (HCFA) recently announced new patient protection standards as a condition for participating in the Medicare and Medicaid programs. Psychiatric hospitals are covered by the new standards, which include the right to be free from restraints and seclusion in any form when used as a means of coercion, discipline, convenience, or retaliation. Nonetheless, if past history is any indication, restraints will continue to be used whenever staff members decide they are necessary, and patients will continue to have little recourse, since restraints are still considered a legitimate form of treatment.

The HCFA has regulations restricting restraint use in intermediate care facilities for people with developmental disabilities and in nursing homes, but in testimony before Congress, William J. Scanlon, the director of the General Accounting Office's (GAO) Health Financing and Public Health Issues within the Health, Education, and Human Services Division, reported that despite such regulations, more than one in four nursing homes nationwide have serious and often repeated deficiencies that result in immediate jeopardy and harm to residents.

> *In brief, we found that neither complaint investigations nor enforcement practices are being used effectively to ensure adequate care for nursing home residents. As a result, allegations or incidents of serious problems, such as inadequate prevention of pressure sores, failure to prevent accidents, and failure to assess residents' needs and provide appropriate care, often go uninvestigated and uncorrected. Our work*

in selected states reveals that, for serious complaints alleging harm to residents, the combination of inadequate state practices and limited HCFA guidance and oversight have resulted in policies or practices that may limit the number of complaints filed; serious complaints alleging harmful situations not being investigated promptly; and incomplete reporting on nursing homes' compliance history. (Congressional testimony of William Scanlon, March 22, 1999, Nursing Homes: Stronger Complaint and Enforcement Needed to Better Assure Adequate Care, GAO/T-HEHS-99-89, March 22, 1999)

If such abuses can go on in facilities where regulation supposedly exists, it is clear that the lesser regulation of psychiatric facilities results in even more abuse and neglect than exists in nursing homes.

Problems with overdrugging and restraints were not the only issues raised by the hearing. Other attendees testified about the devastating effects of electroconvulsive therapy (ECT). Sharon Frieler, a person with a psychiatric disability and a member of a PAIMI advisory council, spoke of witnessing the toll ECT had taken on others.

You lose parts of your life, your memories. I, myself, personally, am against ECT treatments because it is only a band-aid for the person's problems. In many cases, it destroys parts of your life; it does not enhance life. (Sharon Frieler)

In March 1998, the U.S. Department of Health and Human Services released the *Electroconvulsive Therapy Background Paper* prepared by Research-Able, Inc., a Vienna, Virginia, contractor for the U.S. Center for Mental Health Services (CMHS), a component of the Substance Abuse and Mental Health Services Administration (SAMHSA). This 17-page background paper commissioned by CMHS summarized current knowledge, consumer and public views, relevant laws, and research priorities regarding ETC. The report indicated that 43 states regulate the use of ECT, but despite these state laws, "physicians and facilities comply neither with the letter nor the spirit of the laws, nor with professional guidelines." As is typical, people with direct experience of ECT had little opportunity to develop or comment on the report; if they had been given the opportunity for meaningful input, the report would have been far

different. Few subjects within psychiatry arouse such controversy as ECT; the NCD hearing was one of the few opportunities shock recipients have had to testify publicly to a government body about their experiences.

Again and again, NCD heard testimony that graphically illustrated the overall loss of rights experienced by people labeled with psychiatric disabilities. The Wisconsin Coalition for Advocacy, for example, conducted in-depth interviews at a psychiatric hospital in Madison and uncovered:

- coercion to obtain patients' consent;
- failure to honor the requests of people who refused treatment;
- failure to provide patients with sufficient information about the procedure to allow them to make an informed decision; and
- absence of consent for a procedure to treat people who were mentally unable to give consent.

Forced drugging both inside and outside institutions was the source of some of the most painful memories for many speakers. Steven Schwartz, J.D., the director of the Center for Public Representation in Massachusetts, urged careful scrutiny of the efficacy and advisability of the increased and widespread use of outpatient civil commitment and forced treatment. He noted that involuntary treatment laws are in response to the handful of individuals with mental disabilities who have committed acts of violence.

Forced drugging does not occur only within the confines of institutions. Many people testified that involuntary outpatient commitment (IOC) or assertive community treatment (ACT) programs make it possible for people labeled with psychiatric disabilities living in community settings to be required by courts to take medications or risk being institutionalized. According to testimony, some 36 states and the District of Columbia have enacted outpatient commitment laws. The overwhelming majority of those who testified are against such forced treatment.

Joseph Walsh, the coordinator for the Broom County, Recipient Affairs Office in Binghampton, New York, testified that IOC is due to the hysterical reaction to a few very dramatic and highly publicized incidents. Negative media reports incite public fear of and retribution for millions of people labeled with psychiatric disabilities who are law-abiding citizens. Walsh stated that anyone in New York with a psychiatric diagnosis is faced with the prospect of compliance with a judge's order, at the behest of a psychiatrist, to take their medicine, or else.

Nor was he the only person to testify as to the negative effects of IOC:

> *Society is so invested in its search for magic bullet pharmaceuticals that it ignores the innate ability of the individual to effect their own recovery from psychological distress.* (Angela M. Cerio)

In contrast, written testimony provided by Mary T. Zdanowicz, Esq., the executive director of the Treatment Advocacy Center (TAC), expressed concern that laws enacted "to prevent the use of assisted treatment unless individuals present an imminent danger to themselves or others" have a deadly outcome that is evident in media headlines about "violent episodes involving individuals with untreated psychiatric disabilities." In fact, TAC has compiled a database of 400 such incidents. TAC promotes programs for assertive community treatment programs and a repeal of the Medicaid Institutions for Mental Illness exclusion, which prevents Medicaid reimbursement for people between the ages of 21 and 64 who are otherwise eligible for inpatient treatment if a facility has 16 or more beds.

TAC's written testimony endorsing the use of assertive community treatment programs also urged that federal funding priorities be rearranged to encourage states to use commitment standards based on severity of psychiatric disability rather than threat of dangerousness, and to implement outpatient commitment laws. Rael Jean Isaac, who co-authored *Toward Rational Commitment Laws* with D. J. Jaffe, a board member of the National Alliance for the Mentally Ill (NAMI), wrote, "I strongly support involuntary intervention in the case of individuals too sick to know they are sick—which comprises a large portion of the seriously mentally ill."

One mental health administrator described TAC as a well-funded organization that uses double-speak, such as referring to outpatient commitment as "assisted treatment," to appeal to the public's ignorance about people with psychiatric labels.

> *[TAC] argues that people who reject mental health services are too "sick" to have "insight" into our conditions, and thus must be forced to accept treatment. For many people [with psychiatric disabilities], rejecting these services is a rational reaction to their negative experiences in the mental health system.* (Darby Penney)

Steven Schwartz, J.D., of the Center for Public Representation framed his argument against forced treatment in these terms:

> *Massive deprivations of liberty to possibly prevent a small number of incidents should not be countenanced under our system. Legislatures in states that have rejected abandoning civil liberties in the name of treatment, the softening of civil commitment standards, and the imposition of more forced treatment are under pressure to enact laws that make forced treatment easier. There is substantial literature from which to argue forced treatment does not work.* (Steven Schwartz, J.D.)

The overwhelming amount of testimony concerned the harmfulness of involuntary interventions on people's sense of dignity and self-worth, and, further, contended that such interventions were seldom helpful in assisting people either with their immediate problems or with their long-range ability to improve their lives. NCD heard numerous eloquent pleas for services that were responsive and respectful, and which allowed recipients the same rights and freedoms other citizens take for granted. It is important to keep in mind that the hearing was one of the rare opportunities for people labeled with psychiatric disabilities themselves to be the major voice in a government-sponsored inquiry into mental health issues. It is common for mental health policy discussions never to mention words such as "involuntariness" or "force," because these topics are seldom addressed except by people who have suffered because of them. In fact, there seems to be a tacit acceptance among policymakers and the media that people

labeled with psychiatric disabilities "need" to be forced "for their own good," and the question of whether such force belongs in a system of medical treatment rarely is systematically examined.

> *I'm executive director of the National Empowerment Center, a board-certified psychiatrist, and a person with a history of a psychiatric disability. I want to point out, first of all, the importance of people having choice and having a say in voluntary services. As a person who recovered from schizophrenia, I find that the most important elements are having a trusting relationship with somebody who cares about you and can understand you and get to know you, and make it worthwhile for you to return to the community and to some productive role. It's also important that people have resources, have education, jobs, and that these not be under coercive conditions.* (Daniel Fisher)

The independent living movement's demand for self-determination in crafting policy and making decisions on all levels was also frequently echoed.

> *It's just really important to be recognized as another group that is demanding the same thing that people with physical disabilities are asking for, that racial minorities and ethnic minorities and sexual minorities are asking for, and it's the right to speak for ourselves, to represent our own interests, and to be regarded as credible experts on what it is that we need.* (Judi Chamberlin)

> *The first point is that we speak for ourselves.* (David Oaks)

The overwhelming majority of those testifying were against forced treatment. They echoed feelings of abandonment, helplessness, and vulnerability, and called for a total ban of all involuntary treatment and outpatient commitment laws. They also related many stories showing that involuntary treatments are often used when people are not dangerous to themselves or others but only bothersome to relatives or neighbors.

But the popularity of outpatient commitment and other laws that force treatments on people labeled with psychiatric disabilities both inside and outside institutions shows a growing hostility toward these very real sentiments. It is essential that Congress and policymakers hear

from those who are victimized and view the need for such laws with deep skepticism. Quite often, forced treatments are the easy way out. They debilitate people who want to enjoy life and who can be productive if the time is taken to work with them to design proper treatment courses, which usually include assistance with housing, income supports, and other real-life needs. Forced treatments should have to meet a heavy burden of proof that they are indeed the absolute last resort. They represent the worst violations of the right to self-determination.

Self-determination is vital for more than just symbolic reasons. Detached, ivory tower policymaking based on input from experts, and that excludes participation from people labeled with psychiatric disabilities themselves, results in wasteful and ineffective one-size-fits-all public policy that doesn't efficiently meet the needs of those it is intended to serve.

NCD has developed and endorsed a wide array of public policy resolutions and recommendations. Most of them relate to the 10 core recommendations. Much of the body of the larger report lead to the development of those 10 critical recommendations.

Public Policy Recommendations

Government civil rights enforcement agencies and publicly funded advocacy organizations should work more closely together and with adequate funding to implement effectively critical existing laws such as the Americans with Disabilities Act, Fair Housing Act, Civil Rights of Institutionalized Persons Act, Protection and Advocacy for Individuals with Mental Illness Act, and Individuals with Disabilities Education Act, giving people labeled with psychiatric disabilities a central role in setting the priorities for enforcement and implementation of these laws.

Congress should increase DOJ funding to investigate and monitor institutions under the provisions of the Civil Rights of Institutionalized Persons Act of 1980 (CRIPA). When a pattern of abuse and patient rights violations occur, DOJ should promptly investigate and, if warranted, prosecute. Negotiated agreements to improve conditions are worthless if the provisions of such agreements are not monitored to ensure compliance.

Congress should expand the scope of jurisdiction of protection and advocacy organizations and increase and maintain sufficient funding for P&As. P&As have a congressional mandate to investigate incidents of abuse and neglect; however, P&As often have difficulty accessing facilities or records, despite their mandate. Congress should also mandate that people labeled with psychiatric disabilities sit in representative numbers on the governing boards of P&A agencies, not just on advisory councils. The number of people labeled with psychiatric disabilities should be proportionate to the amount of funding for the PAIMI program within the overall P&A budget.

Incidents of deaths, abuse, and other crimes occurring in institutions should be quickly investigated by local police and expert criminal investigators who are independent of institutions. In-house investigations conducted by inexperienced personnel can compromise future criminal and civil litigation.

With the elimination of state funding for prison legal service agencies, it is essential that protection and advocacy services are available to people labeled with psychiatric disabilities in correctional facilities. Congress should increase funding for protection and advocacy organizations to accommodate the increased workload. Current funding levels do not adequately cover enforcement of laws that protect the rights of people with disabilities.

In March 1999, when he introduced H.R. 1313, the Patient Freedom From Restraint Act, Representative Pete Stark (D-CA) said:

> *Documentation of these cases is an essential mechanism for protecting the rights and liberties of the patients.*

People testifying who were subjected to aversive treatments, as well as advocates, attorneys, and others, were so compelling and united on this issue that they command credibility. Congress should ban restraints and other "therapies" such as wet/cold therapy and calming blankets that restrict people's freedom of movement, by linking their use to withholding Medicaid and Medicare reimbursement to providers using such methods unless their efficacy can

be proven through independent research in which people labeled with psychiatric disabilities play a major role. The culture surrounding the use of restraints, isolation, and other aversive therapies must change. Staff should view these methods as treatment failures. Evidence demonstrates that use of restraints and seclusion can be drastically reduced and replaced by effective alternatives when there is a management commitment to do so. Simply restricting the use of restraints may not be sufficient, as systems may simply move to different forms of restraint (such as chemical restraints) or continue their use "informally."

Even proponents of electroconvulsive therapy (ECT or shock treatment) admit that it is a highly controversial procedure. Many of those who have been subjected to it consider it to have been extremely physically and emotionally damaging, and many believe that it has had long-lasting adverse effects, particularly on memory. The stories of those who testified as to the harmfulness of ECT in their own lives were heart-rending, especially since many witnesses were given the procedure without full informed consent, including information about the risks of long-term memory loss.

Nonetheless, neither congressional hearings nor other government proceedings have ever heard from shock survivors and other opponents of shock in representative numbers. More often, the proponents of shock have either authored the reports or had major involvement in writing them, often without disclosing conflicts of interest (such as financial involvement with the manufacturers of shock machines), while opponents of shock treatment have been excluded from the process.

The principles of self-determination dictate that recipients of mental health services should play a major role in the deliberations concerning every issue that impacts their lives.

Chapter 2

Creating New Lives: Independent Housing, Economic Supports, Meaningful Work

The success of the independent living movement in America is due to the authentic resonance of a philosophy of self-determination, in which people with disabilities find strength, support, inspiration, and expertise among their peers. People labeled with psychiatric disabilities place an equally high value on self-determination and interaction with their peers; however, they rarely achieve either.

> *We want to be able to decide for ourselves where we live, how we spend our time, and if we decide that we need some kind of help or assistance in our lives, it should be up to us to say...what kind of assistance we need. And very often...what people desire is not psychiatric assistance but peer support—help from other people who have gone through the same kinds of experience that they have, and who have a gut-level knowledge of what it's like.* (Judi Chamberlin)

A one-day census of inpatient clients conducted by SAMHSA in 1994 reports 236,110 people labeled with psychiatric disabilities were receiving 24-hour hospital and residential treatment—a marked decrease from the 471,452 people who received services at similar facilities in 1969, when deinstitutionalization of people labeled with psychiatric disabilities first began. Unfortunately, during the following decades, as more and more people labeled with psychiatric disabilities left institutions or remained in their communities, federal, state, and local governments failed and continue to fail to provide the needed community-based services, and virtually all of the community services that were provided continued the paternalistic practices of the large institutions they replaced.

Mental Health, United States, 1998, published by the Center for Mental Health Services (CMHS), estimates between 10 and 13 million people in the entire U.S. adult population had a serious mental illness in 1990—the last year such data were collected. (These numbers do not reflect people who were homeless or institutionalized.) Despite such large numbers of people

labeled with psychiatric disabilities, the GAO reports that in fiscal year 1996, SAMHSA block grants to state and local governments totaled only $275 million for mental health services (the vast majority of mental health services funding comes from state and country governments). State and federal funding shortfalls have created gaps and shortages in treatment, housing, and vocational and other services. Further, only a tiny fraction of these funds has gone toward consumer-controlled, peer-run services.

Because of the very real stigma of a psychiatric label and the discrimination encountered by people labeled with psychiatric disabilities, many people with psychiatric diagnoses prefer to hide their status wherever possible. Simply by virtue of their diagnosis or label, people labeled with psychiatric disabilities are perceived as second-class citizens, murderers, people to be feared, people too incompetent to make their own decisions, malingerers, and many other stereotypes.

> *The single greatest need in search of redress is the prejudice and discrimination suffered by people living with mental illnesses. We are discovering that prejudice and discrimination exist everywhere. They exist in the general society, in our system of medical care, justice, and prison systems; even in our electoral system.* (Joseph Glazer)

> *One of the things I've heard the most from consumers is, "We don't want to be schizophrenic or borderline or whatever. That is a diagnosis. That's not me. I am a human being. I don't want to be identified as a borderline."* (Dennis Morrisey)

> *In reality, people with mental disabilities are no more violent than the average citizen. The MacArthur Violence Risk Assessment Study, released in 1998, found that, in the absence of alcohol or substance abuse, people with mental disabilities are "no more likely to be violent than were other people living in their neighborhoods." Said John Monahan, one of the study's authors: "The best epidemiological evidence indicates that major mental disorder accounts for, at most, 3 percent of the violence in American society."* (Treatment by Force Is an Attack on

Rights Perspective by Sally Zinman, executive director of the California Network of Mental Health Clients, *San Jose Mercury News,* June 20, 1999.)

Debbie Whittle is an example of someone who sought treatment from private sources and never received a label.

> *I experienced early trauma, to which I had a set of coping strategies, including disassociation, fantasizing, self-blame, self-hatred. I was afraid of confrontation and rage. I had difficulty expressing anger, yet I cried very easily. I had very low self-esteem, although I looked pretty good and fairly competent on the outside....I never knew what that diagnosis was, if there was one. That is so important. I can't stress that enough. I was never told that my coping strategies were bad or wrong. I was never given the feeling that my attempts to seek help were because there was something wrong with me.*

Whittle reiterates the important distinction of living without a psychiatric label and obtaining help from outside the public health system.

> *What does this story have to do with a hearing on psychiatric disabilities? Everything. Although I consider myself a trauma survivor, I do not consider myself a psychiatric survivor. Why? Because no one ever labeled me that way. I can't help but wonder how different my story would be if I had presented myself to a mental health center. My history is not that different from the majority of folks with psychiatric labels. I can't help but wonder how different most of their stories would be if they had never received a psychiatric label, but were given a chance to heal their losses and traumas without the shame of pathology.* (Debbie Whittle)

The lack of self-determination for people labeled with psychiatric disabilities is most apparent in the area of treatment, because unlike a person with cancer, an individual with a psychiatric disability is rarely offered treatment choices. Instead, treatment decisions are made by psychiatrists, social workers, family members, or others without their knowledge or their

consent, and they can be deprived of their civil rights at a moment's notice should they not accept the offered treatment "voluntarily."

> *As long as we have involuntary commitment laws and forced treatment laws, we are not free citizens. It's really a form of legalized discrimination, and I see that these laws are ultimately incompatible with the Americans with Disabilities Act.* (Judi Chamberlin)

Many people testified that forced involuntary treatments, in addition to depriving individuals of their rights, also caused physical and mental injuries, and even death. Although one advocate and survivor, Darby Penney, last received involuntary drug treatment in an institution more than 20 years ago, she says it still has an impact on her life. Today, she is very conscious of not doing anything that others would consider "crazy enough to lock me up." She says the psychiatric drugs she received left her with physical disabilities.

According to testimony, people labeled with psychiatric disabilities may be held financially liable for their forced treatment, when insurance refuses to cover it or when they lack insurance.

Penney testified that it is illogical for a system with limited and dwindling resources to force people into treatment. She stated that forcing services on people who do not want them takes scarce resources away from people who do, and reported on an evaluation conducted at Bellevue Hospital in New York City, which indicated that there is no difference in outcomes between people who were subjected to outpatient commitment and control groups.

> *If the programs are good, people will come. It's possible for states to make people offers that they won't refuse on a voluntary basis. In Massachusetts, we have no outpatient commitment. We have no involuntary care in our community and are able to provide the care, particularly when the states are willing to invest in the support services, on that voluntary basis, in a way that consumers and psychiatric survivors are willing to participate.* (Steven Schwartz, J.D.)

Because people labeled with psychiatric disabilities encounter shortages of voluntary treatment options, a lack of affordable housing, and insufficient or inappropriate community-based services, many remain in hospitals or jails, or are homeless. John Rio, a housing advocate from the Corporation for Supportive Housing (CSH) in Manhattan, New York, testified:

> *One of the things, from my experiences in the field of mental health, is that a lot of people are in hospitals and in jails and held there unnecessarily, or released into the community without adequate community-based services. At CSH, we think that integrated services can be provided through supportive housing; and one strategy is to try to...pose a solution to this kind of a problem. Unfortunately, we don't have enough, and we need more help with changing policies that support the growth of supportive housing and integrated community services.* (John Rio)

People in institutions are particularly vulnerable. They are isolated from peer support networks and also from legal advocates.

> *They isolate you and they become your only reference point.* (Diana Rickard)

Once people are institutionalized, they may remain in there long after treatment has ended and they are ready for discharge. For example, testimony revealed that in New Jersey, of the approximately 2,000 people institutionalized in five state-run psychiatric hospitals, about 45 to 50 percent of them have been determined to no longer meet any standard of dangerousness, but they continue to be confined because not enough community services are available.

In June 1999, the Supreme Court issued an important decision in *Olmstead v. L.C.*, which tested the strength of Title II of ADA. The case concerned two women with psychiatric disabilities who asked to receive services in their communities instead of institutions. The Court ruled that when a professional determines that a person with a disability can live in the community effectively, he or she *must* be offered this choice. To do otherwise is discrimination. There are several caveats in the Court's decision, however. Individuals cannot self-determine where they receive services, and they can receive community-based services *only* if such

alternatives exist. Currently, adequate community-based alternatives simply do not exist in sufficient numbers to allow all people who might qualify under the Olmstead rationale to leave institutions. This problem may be exacerbated in the future since some states have submitted lawsuits challenging Congress's legal authority to mandate that states comply with Title II of ADA.

A lack of affordable housing is another barrier to the community integration of people labeled with psychiatric disabilities. A federal law some people cited as exacerbating the shortage of housing for people labeled with psychiatric disabilities was the Housing and Community Development Act of 1992. Among other things, this law allows public housing authorities to designate for use exclusively by elderly people units that were previously available to both elderly people and to younger people with disabilities. Thus, younger persons with disabilities are no longer eligible to move into these federally funded buildings. Roy Neville, a housing advocate, testified:

> *Mentally ill people got cut out of apartments and public housing projects that the elderly want for their own. That's discrimination.* (Roy Neville)

Neville testified that HUD has attempted to compensate for these cuts by increasing the number of rent supplement programs that provide vouchers and certificates for people with disabilities to obtain housing, but notes:

> *The public housing agencies don't apply for [these programs], because the application process is too complex.* (Roy Neville)

Impact of Designated Public Housing on Persons With Disabilities, a 1998 GAO report, however, concluded that the 1992 law has "had little impact" on the availability of public housing for people with disabilities. But it also noted:

> *It is too soon to determine the extent to which the Section 8 rental certificates and vouchers set aside for persons with disabilities have helped meet this population's needs.* (Impact of Designated Public Housing on Persons With Disabilities, GAO/RCED-98-160, June 1998)

At the time of the GAO review, an Anaheim, California, housing authority had not yet issued any of the 150 vouchers it had received from a mainstream housing program. The housing authority indicated that it expected that all 150 vouchers eventually would be used, however, and it planned to apply for more vouchers since it had 1,500 persons with disabilities on its waiting list. Apparently, this problem extends beyond Anaheim, as Neville testified:

> *Last summer, over 7,000 Section 8 new certificates and vouchers for people with disabilities were available to communities in New York State, but public housing authorities [failed] to apply for them. We need incentives to make these units available.* (Roy Neville)

Ruth Lowenkran, a legal advocate for the Disability Law Center in Albany, noted that other forces are at work to weaken the protections of the Fair Housing Amendments Act of 1988 (FHAA):

> *There are constant pushes in Congress to eviscerate the protections of the Fair Housing Act, and to narrow the scope of persons protected, and narrow it [to] eliminate the protections for persons with psychiatric disabilities.* (Ruth Lowenkran)

An example is H.R. 3206, the Fair Housing Amendments Act of 1998, which, if enacted, would have repealed civil rights protections for people with disabilities and subjected them to renewed discrimination by zoning officials and hostile neighbors. The bill also would have permitted local governments to completely zone out group homes and other community living arrangements. Disability advocates succeeded in fending off this threat. However, there was much testimony indicating that this is a constant battle.

The executive director of the New York State Alliance for the Mentally Ill, Glen Liebman, testified that his organization surveyed its membership on housing. It found that the majority of adult children living with their parents wanted to leave home, but there were no housing options available for them.

> *We have 143,000 people in New York state with a serious mental illness who use some kind of mental health services. Out of that number, there are 20,000 in some*

kind of state-supported housing, there are about 6,500 people in state psychiatric hospital beds, and another 11,000 in adult homes. Even if you acknowledge that there are 10,000 people with mental illness in the shelter system, this still means that less than a third of mental health recipients are in housing outside the family. (Glen Liebman)

One result of the lack of affordable housing is the prevalence of homelessness among people labeled with psychiatric disabilities.

Where's everyone else? The bottom line is, either they're living still at home with their family, they're in prison, they're homeless, or they're in a shelter. (Glen Liebman)

The National Resource Center on Homelessness and Mental Illness reports an estimated 600,000 people are homeless in the United States on any given night. Approximately 200,000 of these individuals have serious mental illnesses, such as schizophrenia, bipolar disorder, or major depression, and at least 50 percent of homeless people with serious mental illnesses also abuse alcohol, drugs, or both. Lucy Kim, who is now the administrative coordinator for the Center for Urban Community Services, received Social Security benefits for seven years and testified about her periods of homelessness during that time.

Two of...the seven years, this last span that I was disabled, were spent living in a welfare hotel. And, during that time, I experienced depression, apathy, fear, substance abuse. (Lucy Kim)

Several factors are cited as the primary contributors to homelessness in people labeled with psychiatric disabilities, but blatant discrimination is the most prevalent. Testimony consistently revealed that people labeled with psychiatric disabilities are treated separately and unequally.

In Schenectady, a tenant was being forced out because he made noise in his apartment, and his behavior bothered another tenant. (Roy Neville)

People with mental disabilities are being scapegoated as violent, dangerous [people who] shouldn't be allowed to live in integrated settings with other people. Again, [that is] in spite of the fact that statistically, we're no more likely to commit crimes than anyone else. (Judi Chamberlin)

Also, many people labeled with psychiatric disabilities are institutionalized simply because crisis centers, homeless programs, and emergency shelters are inaccessible or ill-equipped to deal with them. Further, they find it difficult to access permanent housing because of pervasive discrimination. Even with the current FHAA protections in place, landlords and local officials either are unfamiliar with the antidiscrimination provisions of the law as they apply to people labeled with psychiatric disabilities, or they simply ignore them.

Currently the provisions of the federal Fair Housing Amendments Act of 1988 provide good protection against housing discrimination for people with disabilities. Unfortunately, many local jurisdictions and local governments are unaware of this law or are trying to overturn it. (Stacie Hiramoto)

Testimony also revealed that mandatory participation in programs and services, such as substance abuse programs or more often "medication compliance," is frequently required by people labeled with psychiatric disabilities as a condition to obtain housing or other services.

There should be an unbundling of treatment from housing. Many people choose homelessness rather than submit to psychiatric treatment in enforced spaces. (Daniel Fisher)

The confusing array of government programs is difficult for people labeled with psychiatric disabilities to navigate. In 1996, the GAO reported that all people with disabilities received services through 130 different programs, 19 federal agencies, and a multitude of public and private agencies at the state and local levels, all with varying eligibility criteria.

People labeled with psychiatric disabilities can receive benefits from a variety of federal, state, and private programs such as Medicaid, Medicare, Social Security Disability Income

(SSDI), Supplemental Security Income (SSI), various veterans benefit programs, food stamps, workers' compensation, unemployment insurance, private disability insurance, and others.

In many existing federally funded income support programs, eligibility requirements differ. An individual may be eligible for services from one program and ineligible for another, simply because a different definition of disability is applied or because the individual carries a dual diagnosis. As a result, individuals are required to endure a series of application processes.

> *One of the most contentious aspects of disability research is also the most basic—the definition of disability. Different federal programs use different operational definitions of disability, as do researchers, advocacy groups, and other interested parties.* (People with Disabilities: Federal Programs Could Work Together More Efficiently to Promote Employment, GAO/HEHS-96-126)

Testimony also revealed that eligibility criteria are frequently confusing and more stringent for people labeled with psychiatric disabilities than for people with other disabilities. As of December 1997, some 1.1 million people received SSDI benefits, and another 1.2 million received SSI benefits for mental disorders. However, testimony revealed that when people labeled with psychiatric disabilities apply for SSDI or SSI benefits, they face frequent denials, long waits, or stressful appeals. They also encounter a higher rate of denial for initial benefits. In 1997, GAO reported that 39 percent of people with mental illness were initially denied Social Security benefits—a much higher percentage than for other people with disabilities.

Jessica Wolfe testified that her initial claim for Social Security benefits was denied, and she has waited two years for an appeal hearing. Meanwhile, she has no money for therapy, has depleted the family's savings, and she buys food with credit cards.

> *I understand that there will be a psychological evaluator at the hearing to give testimony about whether my symptoms are severe enough to prevent me from working [at] any job. You know something? According to them it doesn't matter that I cannot make a living....My best hope is getting SSDI, and I am scared I will not get it.* (Jessica Wolfe)

As my consumers and my people get to the point where their mental illness prevents them from working, the first hurdle they face is that the applications that they have to fill out for disability and SSI have nothing to do with mental illness. (Dennis Morrisey)

According to GAO, differences in assessments of functional capacity, different procedures, and weaknesses in quality reviews contributed to the Social Security Administration's (SSA) inconsistent decisions. In 1994, SSA began implementation of a disability redesign process that, among other things, will eventually streamline the claims and appeals process. It is expected to be fully implemented in FY 2001.

Roy Neville expressed concern that many people who have psychiatric disabilities but do not have a long-standing diagnosis of severe mental illness are ineligible for SSI or have been dropped from SSI rolls, and are left without financial or other supports.

These people drop out of the safety net...and [are] made to get into the welfare-to-work requirements. They're being cut out of food stamps and child care, job training, and emergency food. And some of them are mothers with children. The number of poor people who visit food pantries in New York is rising rapidly. And there needs to be a safety net for these people who have mental disabilities in the welfare-to-work program. (Roy Neville)

Employer-sponsored short- and long-term disability insurance plans frequently discriminate against people labeled with psychiatric disabilities. NCD heard testimony from a former employee of a Fortune 500 company who received almost six months of short-term disability payments from her employer of three years. But before she was eligible for long-term disability benefits, she was notified that her benefits would end. A few days later, her employment was terminated. She currently receives SSDI, but believes that she would not have been denied long-term disability benefits if her disability were not psychiatric. She has filed a lawsuit based on discriminatory treatment. This case is not an isolated example but is typical of long-term disability insurance practice of unequal benefits for psychiatric versus physical disabilities.

People labeled with psychiatric disabilities who attempt to return to work face numerous hurdles. State-federal vocational rehabilitation (VR) programs, which are directed by the Rehabilitation Services Administration (RSA) and which deliver services through state and privately operated agencies that provide education or training, have not been notably successful in assisting people labeled with psychiatric disabilities.

> *GAO did find that states purchased more services for clients with physical than with mental disabilities, more for clients with severe than with non-severe disabilities, and more for white clients than for black, Hispanic, or American Indian clients.* (Vocational Rehabilitation: Evidence for Federal Program's Effectiveness Is Mixed, GAO, August 1993)

It appears little has changed in the ensuing years. Bernice Loschen testified to NCD that:

> *People labeled with psychiatric disabilities need to be given equal treatment services as everyone else, so they'll have a fair chance to get the advocacy help that they need to get a job, [the same] as any other client of [VR], as persons who use wheelchairs, who are blind, and who are deaf—and this isn't happening now. These persons deserve [the same] dignity and respect as anyone else does.* (Bernice Loschen)

John Rio, of the Corporation for Supportive Housing in New York City, testified that new strategies are needed to place people labeled with psychiatric disabilities in worthwhile careers.

> *Individuals with psychiatric disabilities have a right to employment opportunities and the services necessary to participate in America's workforce. While many areas of the country enjoy a healthier economy, our clients are not participating to the fullest extent possible. We think we need to see more involvement from the private sector, particularly in employer-based training strategies. These strategies are important because we need to help clients not just get an entry-level job but to start on a path of employment that will lead to livable wage careers.* (John Rio)

Rio testified that seven years ago the National Advisory Mental Health Council, in coordination with the federal Interdepartmental Task Force on Homelessness and Severe Mental

Illness, held hearings in Chicago and published its findings and recommendations. He notes that although some improvements occurred in the service delivery systems, most cases continue to "fall short of the mark." In fact, he stated, a number of recommendations resulting from those hearings still need to be addressed, including:

- greater coordination between federal, state, and local programs serving people labeled with psychiatric disabilities;
- expanding anti-stigma activities to dispel harmful misconceptions, especially among employers; and
- creating a wide variety of permanent housing options with supportive services that include employment opportunities.

Rio noted that the Balanced Budget Act of 1997 offered a provision for states to buy into Medicaid by adding a category for people with disabilities who are working. He says, however, only Oregon has successfully made this option available, "but not without great difficulty from the Health Care Financing Administration (HCFA)."

He testified that he is encouraged, however, that nearly half of SSA's 12 demonstration projects to test effective strategies for coordinating state workforce systems to help people with disabilities return to work and decrease their reliance on public supports have elected to focus their projects on people labeled with psychiatric disabilities, and stated further that other states should consider waiver-based work incentives that are not funded in the SSA demonstration projects. He did perceive a shortcoming, however.

> *As you know, the key to these projects is likely to rest in waiver-based work incentives. And guess what? These waivers will need to be [approved by] HCFA. We expect this will be an extraordinary challenge for states...the states need a partner in HCFA that shares the goal of helping people with disabilities work or work more. This is a matter of public policy.* (John Rio)

Many people reported that vocational outcomes are more successful in community programs that offer a number of services, such as housing, training, and health care. An example is Next Step: Jobs, an employment initiative funded by the Rockefeller Foundation in 1995, in which 21 nonprofit supportive housing agencies partnered with the Corporation for Supportive Housing in New York to increase the rates of employment among people in supportive housing who faced multiple barriers to employment. The project demonstrated that supportive housing offered a basic, critical ingredient for positive vocational outcomes—that is, continuous case management, permanent housing, and a culture supportive of working tenants. However, it is important to note that such a model is unacceptable to many people labeled with psychiatric disabilities who want to work but will not attend programs that require them to accept other services they do not want.

In addition, the National Institute on Disability and Rehabilitation Research (NIDRR) has funded several studies that evaluate model employment programs, such as *Outcomes and Career Achievements of Persons with Professional Qualifications Who Have Severe Psychiatric Disabilities: The Minnesota Mainstream Experience*. In sharp contrast to the widely held belief that people labeled with psychiatric disabilities cannot work, or can work only at menial jobs, there are a number of program models showing that people labeled with psychiatric disabilities can obtain and retain employment if they have the supports they want. It is essential that such supports are not "one size fits all," but are individually chosen according to what the individual in question finds helpful.

Peer support is an important component of successful community reintegration; however, it is often unavailable. Several people testified that a lack of peer support for people labeled with psychiatric disabilities contributes to their isolation from other people labeled with psychiatric disabilities as well as other segments of the disability community.

> *We need to find a way to have HCFA...fund the extraordinarily important consumer-run services which play a vital role in helping people to emerge from the mental health system and not remain a mental patient for life.* (Daniel Fisher)

Public Policy Recommendations

It is crucial to ensure that people labeled with psychiatric disabilities have control over programs and services that directly affect them.

People labeled with psychiatric disabilities should be fairly represented on boards of all agencies and programs that provide services to this population and that receive federal funds. In addition, programs that serve all disabilities need to ensure that consumer representation on their boards includes those with psychiatric disabilities.

Congress should establish an oversight group composed of people with disabilities—including significant numbers of people labeled with psychiatric disabilities—to advise SSA and Congress on the effectiveness of SSA policies and procedures, as well as the future of its various programs, including SSDI, SSI, Medicare, and Medicaid.

User-managed peer support programs controlled by people labeled with psychiatric disabilities should be supported with increased federal funding. Public policy should encourage self-help approaches as the best way to promote self-determination.

Medicare and Medicaid waivers should be expanded to support peer-run programs. HCFA rules should be revised to provide broad latitude and financial incentives for such services, in line with self-determination approaches for those with physical and cognitive disabilities.

Congress should fund additional community-based programs to eliminate "warehousing" of people labeled with psychiatric disabilities in institutions. The fact that large numbers of people labeled with psychiatric disabilities who want to live in the community are unable to do so because there is insufficient funding for community programs should be considered a policy failure. The institutional bias in funding must be addressed in ways that encourage community living and self-determination.

People labeled with psychiatric disabilities should be offered a menu of available services and programs to choose from, including mental health services, peer support, housing, vocational training, and employment. People labeled with psychiatric disabilities should be free to reject any or all services, and should be able to access those that they want without being required to participate in others.

HUD 811 regulations already contain a prohibition against mandatory services for projects supported by these funds. This should be expanded to cover all federally funded housing programs, including local and private housing programs for people with disabilities that receive federal funds. The responsibilities of tenants with disabilities should be no greater than those of all other public housing tenants—paying rent, maintaining a clean home, and so on.

HUD should increase affordable housing for people labeled with psychiatric disabilities and combine all of its housing programs for people with disabilities—regardless of disability or chronic health condition.

Using a cross-disability approach to disability would offer efficient and equitable delivery of services. Finally, segregating people by their disabilities into specific housing and other federal programs is discriminatory, creates barriers to services, and divides the disability community, as well as creating "disability ghettoes."

Testimony consistently revealed that homelessness and the lack of affordable housing for people labeled with psychiatric disabilities are major concerns, an indication that existing HUD funding levels do not meet the demand.

Congress, therefore, should increase HUD funding for integrated, community-based housing for people with disabilities to include financial incentives for entities providing supportive services.

While Homeless Assistance Programs (HAP) and Housing Opportunities for Persons with AIDS (HOPA), saw significant increases in funding, HUD's FY 2000 budget provides only

$194 million for Section 811 housing for people with disabilities—no increase from HUD's FY 1999 or 1998 budgets.

HUD should exert tighter oversight over the distribution of Section 8 vouchers and certificates to eliminate the backlog of people waiting for housing.

HUD should assign Section 8 voucher certificates to all people who leave institutions, residential facilities, and nursing homes, as well as people eligible for Medicaid home and community-based waivers.

This would eliminate some of the warehousing that was discussed in testimony and offer a safety net for people who are in transition from institutions to communities.

HUD should establish a guaranteed loan program targeted at all people with disabilities so that they can own their own homes.

Funding for such a program could be obtained by eliminating or reducing HUD's 232 program, which provides low-interest loans to owners of nursing homes and assisted-living facilities.

HUD should ensure that priority is given to qualified consumer-run disability organizations, such as independent living centers, to administer the agency's housing programs for people with disabilities.

On March 8, 1999, HUD announced the availability of $48.5 million for new tenant-based rental subsidies for people with disabilities—including people with severe mental illnesses—through the Mainstream Housing Opportunities for Persons with Disabilities Program. For the first time, this funding was made available to nonprofit disability organizations, as well as to public housing agencies (PHAs) deemed qualified to administer the program. Qualified agencies operated and controlled by people with disabilities should administer housing programs for people with disabilities. Nonprofit organizations that are not controlled by people with disabilities should not be eligible.

Congress and the administration should continue to block further attempts to designate elderly-only housing and all attempts to remove or reduce the anti-discrimination protections of the FHAA.

Congress should authorize an independent evaluation of all HUD programs and services for people with disabilities, to ensure compliance with existing laws, as well as efficiency and accessibility of HUD operations and federally funded HUD programs and services.

The evaluation should include recommendations for improvements and equitable methods of service delivery.

One of the few legal recourses left to victims of disability-based discrimination in housing is the FHAA. Excluding people labeled with psychiatric disabilities from housing is tantamount to endorsing discrimination based on stereotypes that would not be tolerated against any other segment of the population.

Therefore, HUD should launch a comprehensive and sophisticated nationwide audit to test and evaluate disability-based housing discrimination in urban, suburban, and rural communities around the nation, similar to the audit announced by HUD in November 1998 to combat discrimination against other minorities.

HUD should initiate an awareness and training program that educates people with disabilities, as well as local housing officials, landlords, and others receiving federal funds, about the protections afforded people with psychiatric and other disabilities under the provisions of the FHAA. Recipients of HUD funds, including local housing authorities, should be required to attend mandatory training and demonstrate a minimum level of FHAA-disability-related competency and awareness before HUD funds are released to them.

Also, local independent living centers or similar client-run groups should be contracted to conduct voluntary awareness training for realtors, leasing agents, and others who do not receive federal funds but who would benefit from such training.

DOJ and HUD should enforce vigorously the provisions of both the Rehabilitation Act and FHAA, and aggressively pursue legal action in instances where people with disabilities are denied access to federally funded programs and services or encounter housing discrimination. These actions would send a message that the laws are strong and that discrimination will not be tolerated.

Increase a wide array of employment opportunities geared to utilize the interests, skills, talents, and expressed wishes of people labeled with psychiatric disabilities.

The successful components of employment demonstration programs should be implemented while the identified weaknesses should be addressed. Information about successful programs should be disseminated and shared among agencies, task forces, committees, and others concerned with employment of people with psychiatric disabilities, and directly with people with disabilities themselves.

HCFA should revise existing regulations to make it easier for states to apply for Medicaid waivers under the Balanced Budget Act of 1997 for people with disabilities who return to work.

The employment experiences of people labeled with psychiatric disabilities and their interactions with training providers and the state-federal vocational rehabilitation systems should be included in the development of any employment training programs.

SSA should implement a disability determination policy that is consistent and fair. Disability determination specialists should receive ongoing training on the new policies and how they may apply to people labeled with psychiatric disabilities.

Congress should mandate that SSA and other federal agencies, as well as state, local, and private agencies receiving federal funds, review applications and other documents to ensure that the information contained in them is applicable, accessible, and does not violate the rights of people labeled with psychiatric disabilities.

Congress should allocate additional funding to accelerate implementation of SSA's disability redesign policy and eliminate the existing backlog in SSA appeals.

Congress should enact legislation that ensures that welfare-to-work programs do not deny people with less severe psychiatric disabilities access to income and other supports and should implement a policy that provides short-term income supports.

Congress should enact mental parity laws for short- and long-term public and private disability insurance plans.

Chapter 3

Patients' Rights: Parity, Alternatives, Inclusion

Because the mental health system has historically been designed and implemented without the participation of people labeled with psychiatric disabilities, there are numerous examples of the ways in which the system does not meet people's self-defined needs.

> *People labeled with psychiatric disabilities should be at major policy decision-making meetings. We are excluded systematically, we don't have the rich lobbyists, we don't have the pipeline into Washington. The policy wonks are the ones that are making all these decisions about us and for us, and we need to find a way to get our people represented in a genuine, participatory fashion, in housing decisions, Social Security decisions, and HCFA health care decisions.* (Daniel Fisher)

NCD heard a great deal of testimony concerning people's frustrations with a system that consistently forces them to accept services they do not want while denying them access to or coverage for those things they find helpful.

> *In order to recover, one needs to find peer support, and in order to do so, one needs to have alternative healing techniques, one has to have access to those kinds of people and treatments that one can control oneself, and not perpetually have to be dependent on medication and doctors, and a psychiatric system that does not necessarily have our best interests at heart.* (Daniel Fisher)

Parity in insurance coverage for psychiatric disabilities, meaning coverage equivalent to that for physical illness, has been promoted on the state and federal level as a major route toward improving access to mental health care. According to testimony, the most blatant discrimination may be found in the very health care system that is intended to serve people labeled with psychiatric disabilities. A lack of mental health benefit parity prevents people labeled with psychiatric disabilities from seeking and obtaining quality, affordable treatment, delays their recovery, and may even exacerbate their disabilities.

It cost the insurance companies and the system a bundle, because my problems, in fact, were so multiplied rather than diminished by my entrance into the mental health system. (Mary Wimberger Auslander)

While many people labeled with psychiatric disabilities are denied even basic treatment options, health care plans cover treatments for physical conditions with far fewer restrictions and exclusions. Joseph Glazer, president and CEO of the Mental Health Association in New York State, testified about the difficulties this causes for people seeking treatment.

It would be unthinkable for our health care system to tell a person, "Yes, you need a kidney transplant, and there is actually one available right now. But we're going to make you wait six months, doing painful treatment and dialysis every day, even though we know that it will be cheaper and more effective in the long run to do the transplant now." It sounds absurd, but that happens to people living with mental illnesses every day. (Joseph Glazer)

Glazer further testified that the inherent structure of the existing system, driven by providers and the insurance industry, is self-limiting because people cannot pursue their own wellness. He testified that barriers to the most effective treatments exist. For example, before some insurance companies will approve newer, more effective drugs, people labeled with psychiatric disabilities are required to demonstrate that older, side-effect-laden pharmaceuticals are ineffective or cause adverse reactions.

For a person living with kidney disease, complete and thorough treatment is always an option. For a person living with mental illness, artificial restrictions are imposed nearly every step of the way. (Joseph Glazer)

Disproportionately large copayments and deductibles for people labeled with psychiatric disabilities pose barriers to voluntary treatment. For example, one person with major depression, as well as posttraumatic stress and borderline personality disorders, testified that she receives mental health benefits through her husband's employer. Although she cannot afford to stop her therapy or her medication, she reports the financial burden may soon leave her no other choice,

since her existing mental health benefits are limited and her out-of-pocket expenses are high. She also cannot obtain affordable supplemental mental health insurance to help defray some of the cost of treatment. While a plethora of supplemental insurance plans exist to cover physical conditions, company policies offering supplemental insurance for mental conditions are almost nonexistent. When supplemental health insurance policies do cover mental health benefits, the annual limits may be as low as $500—much lower than supplemental benefits covering physical health conditions.

> *The lack of mental health parity laws add up to nothing less than societally sanctioned torture.* (Joseph Glazer)

As a result of the limits imposed by restricted mental health benefits, people labeled with psychiatric disabilities cannot control their own lives, are denied the opportunity to make informed choices about treatment, and are forced into unwanted treatments.

There is, however, another side to the question of parity, one that has seldom been aired in the public policy discussions on this issue.

> *Another issue are the so-called insurance parity laws, which promote only one kind of parity. Parity means equality, and if we want to promote equality on the payment side, it's got to come hand-in-hand with equality on the rights side. So, any so-called parity laws are not really equal unless they say that the medical treatment should be offered on the same basis for these diagnoses as anything else, where you cannot be forced. A diagnosis of cancer or heart disease or anything else doesn't carry with it the power to commit and force treatment and neither should any mental health treatment, and if insurance parity as currently written goes into effect, it's just going to be a cover for a lot more forced treatment.* (Judi Chamberlin)

> *We believe that healing and recovery are possible only in an atmosphere in which we control our own lives and make free and informed choices about treatment.* (Darby Penney)

The Mental Health Parity Act (MHPA) of 1996 (P.L. 104-204) required that, beginning in 1998, limited mental health parity—elimination of annual and lifetime dollar limits for mental health care—be made available for all U.S. group health plans that already offer mental health benefits and serve more than 50 employees. However, the law has flaws. The law exempts employers with 50 or fewer employees and those who can demonstrate an increase of 1 percent or greater in total annual health premium costs as a result of mental health parity. Under MHPA, the "sunset" provision mandates that the requirements of the law will cease to apply to benefits for services furnished by an employer on or after September 31, 2001. This law overrides the Employment Retirement Income Security Act (ERISA) exclusions that had exempted from state-level parity legislation at least one-third of the population covered by self-insured employers.

According to testimony, one of New York State's largest managed care insurers responded to the parity law by simply eliminating dollar caps on mental health services and replacing them with annual and lifetime visit caps. A mental health administrator testified that this benefit limitation is additionally grievous to youths between the ages of 18 and 21, who are most commonly diagnosed with schizophrenia and many forms of depression during this time of their lives.

They just did the math and circumvented the law. (Joseph Glazer)

But because the public policy debate on parity has not involved people labeled with psychiatric disabilities in meaningful ways, the question of forced treatment has not been addressed in existing or proposed mental health parity laws. Using the cover of mental health parity to pay for treatments that are not sought or wanted by their recipients will simply make such laws a vehicle to further legitimize and fund involuntary treatment, which is incompatible with self-determination principles. In addition, mental health parity laws could lead to even greater medicalizing of people's problems, because they would fund drugs, electroshock, and hospitalization, when what is often needed are such nonmedical services as improved housing and peer support.

States that have instituted parity laws are turning to managed mental health care to save money. According to *Parity in Financing Mental Health Services: Managed Care Effects on Cost, Access, and Quality*, a 1998 report by the National Advisory Mental Health Council (NAMHC), implementing parity in systems already using managed care results in an increase of less than 1 percent in total health care costs during a one-year period. NAMHC also reports that in systems not using managed care, introducing parity with managed care results in a 30 to 50 percent reduction in total mental health costs. The report notes, however, that considerable variability has been observed in access and other measures of quality across managed behavioral health plans, raising concern about the quality and outcome of mental health care in some plans. In some instances, managed mental health services also have resulted in limited mental health access, decreased work performance, increased absenteeism, and greater use of medical services. Despite its cost-effectiveness, NAMHC reports that only 15 states had enacted mental health parity laws in 1998.

It is important to note that this report, typical of public policy discussion in this area, does not even mention involuntary treatment, despite the emphasis put on forced treatment in much of the testimony heard by NCD.

> *The results of a major survey of employer-provided health plans was published in 1998 by the Hay Group, an independent benefits consulting firm. The Hay Report showed a major decline in benefits in the past decade: Employer-provided mental health benefits decreased 54 percent, while benefits for general health decreased only 7 percent. Even before this erosion occurred, mental health benefits made up only 6 percent of total medical benefits paid by employers. Today, that has been cut in half—it is down to 3 percent. The number of plans restricting hospitalization for mental disorders increased by 20 percent.* (Senator Paul Wellstone (D-MN), Congressional Record, April 14, 1999.)

On June 7, 1999, the U.S. Office of Personnel Management (OPM) notified all of its 285 participating health plans that they must offer full mental health and substance abuse parity to

continue to participate. OPM surveys revealed that health benefit parity would add minimal cost to existing premiums and would increase employee productivity.

Testimony also pointed to problems faced by people labeled with psychiatric disabilities when they return to work and need continued insurance coverage. At the time of the hearings, people labeled with psychiatric disabilities who received Medicaid lost those health benefits if they returned to the workforce, but benefits to Medicare recipients continued for three years after they returned to work. Medicare recipients also have restrictions placed on mental health benefits. Inpatient mental health benefits, for example, have a lifetime cap of 190 days. Beneficiaries also are responsible for 20 percent of the inpatient hospital charge, as well as the deductible for each stay. Medicare coverage for outpatient mental health services is limited to 50 percent of the Medicare allowable charge; however, there is no lifetime cap for outpatient therapy. Medicaid mental health benefits vary from state to state.

The President signed into law the work incentives legislation that includes provisions that allow people to continue Medicaid and Medicare benefits for a period of six years after they return to work. An employer who offers health care benefits should include mental health parity. Unless mental health parity legislation for voluntary treatment is enacted nationwide, at the end of six years many people labeled with psychiatric disabilities will face the same dilemma they face today—a lack of coverage for voluntary treatment and a disincentive to work.

Furthermore, parity alone does not guarantee access to mental health care. With limited available health care dollars, many providers are turning to managed care organizations (MCOs) to provide cost-effective mental health services. Unfortunately, this move is often at the expense of, and detrimental to, the well-being of people labeled with psychiatric disabilities. As an example, an MCO may require "treatment" by a psychiatrist when a client needs and wants therapy or consulting by a non-psychiatric mental health professional.

Arthur Springer developed an anxiety disorder secondary to his physical disability, but he did not obtain competent treatment for his psychiatric disability until six years later, and only after numerous agencies denied him or created insurmountable barriers. He testified that the long process aggravated *both* his physical and his mental health conditions, and is concerned that it

will become more difficult for others to obtain preventive services if Medicaid continues to shift to compulsory managed care.

> *I have been in two widely publicized Medicaid managed care plans since 1991, and it is because of that personal experience, corroborated over and over again by the experiences of many other people that I have met, that I am against managed care for people with chronic, disabling, or rare conditions, until the federal government and the health insurance and HMO industry can explain to me how managed care is safe and effective for me and all others like me. The second issue is the deeply disturbing doctrine of so-called special needs as a rationale for preferential status and services in Medicaid managed care for a few providers. In New York, the state and HCFA propose to create so-called special needs plans for people with HIV/AIDS and serious and persistent mental illness. No one disagrees with the idea that both these groups need a variety of services from people who are qualified to serve them. The issue is the government's refusal to guarantee equitable services, proportionate to need, for all other Medicaid recipients with acute, chronic, disabling, or rare conditions that require something other than so-called primary care.* (Arthur Springer)

> *The most eye-opening discrimination is that found in the very health care system that is intended to serve people living with mental illnesses. The inherent structure of our system, driven by providers and the insurance industry, starts by steering us away from nonmedical options for treatment. By design, it is self-limiting in the kinds of things people can pursue in seeking their own wellness. In practice, under managed care, it has become even more limited, particularly on the mental health side of the managed cost ledger. We know that restrictions on access to the best and most successful medications is practiced, based on cost, and that benefits for nondrug therapies are greatly limited.* (Joseph Glazer)

The director of the Mental Health Legal Advisors Committee (MHLAC), an agency of the Massachusetts Supreme Judicial Court, testified that more states are contracting with private

MCOs to provide Medicaid services because of financial incentives inherent in a for-profit, capitated, closed-network system.

> *In Massachusetts, services are cut based on financial, not clinical, considerations. The amount of therapy each individual receives has been slashed, and greater reliance has been placed on medication services (medications are not paid for by the managed care company). A 15-minute medication session once a month is much less expensive than weekly therapy.* (Frank Laski)

Laski further testified that the quality of care is also affected since managed care has put financial pressures on providers, who have cut staffing or employed less educated staff and foregone staff training.

> *Hurried interaction and even human rights abuses are facilitated by a system with too few staff who can take the time to listen to a client's needs and respond appropriately.* (Frank Laski)

According to MHLAC, although some providers in closed, managed care networks would like to, they cannot directly or indirectly criticize the treatment decisions made by MCOs. If providers disagree with the treatment decisions imposed by MCOs, few appeal because they fear retribution, in the form of cuts in referrals or other limitations on services. Providers also are cautious about recommending too many services for their clients.

> *Under a managed care system, it is very difficult—very, very difficult—for persons with mental illness to look to clinicians or others who are caring for them to be their advocates for their service needs, because they're caught up in the same issues.* (Frank Laski)

Unfortunately, many MCOs are operating with little or no oversight. Testimony from Laski illustrated the problems in Massachusetts, one of the states that has gone furthest in turning Medicaid-funded mental health services over to MCOs. He testified that Massachusetts has been unwilling or unable to effectively monitor the impact of privately managed care. One MCO operating in Massachusetts, for example, received an award for keeping seven-day recidivism

rates at or below 5 percent. MHLAC reports further investigation revealed that recidivism rates were not measured by readmissions for the same diagnosis, and doctors admitted changing diagnoses to reflect lower recidivism rates.

> *In this age of public scrutiny as to how tax dollars are spent, it is befuddling how little the Commonwealth knows about the performance of its Medicare contractors.* (Frank Laski)

Laski referred to an independent study of the privatization of Massachusetts Medicaid mental health management performed in 1993 in Massachusetts that failed to fully address such basic issues as access to services. The absence of this information precipitated the Massachusetts legislature to require quarterly reports from the state's Division of Medical Assistance (DMA). However, no consumer satisfaction survey has ever been performed. MHLAC also reports that the Commonwealth had to increase bonuses because it reduced the amount of money the company could retain if it cut services.

> *The result is that services continue to be cut—no private company would risk loss or forego the opportunity to make two million dollars—and the Commonwealth awards the MCO for performing already promised services.* (Frank Laski)

Glen Liebman, the executive director of New York State National Alliance for the Mentally Ill, testified that he consistently hears from members of his organization that Medicaid managed care plans lack coordination and accountability. His greatest fear is that many of these "special needs" plans "cherry-pick" by only treating healthier people and dropping people with more severe conditions.

Ann Mathes testified that fighting for benefits adds additional stress to the lives of people labeled with psychiatric disabilities. She was surprised when the Medicare carrier for Minnesota changed its policy and informed her psychologist that services exceeding 20 sessions during 1997 would be denied. After much stress and many letters and telephone calls to the local Medicare carrier and HCFA, her therapy sessions were finally covered.

Mary Wimberger Auslander, a psychiatric survivor and mental health professional, testified that she was involuntarily committed to institutions for seven or eight months over a period of nine years. These intermittent hospitalizations only lasted as long as her insurance benefits covered them, and were both expensive and ineffective. As a result, she testified that the months in the institutions cost her at least an entire decade of her life.

> *I learned primarily that the last place you can go to have a nervous breakdown is a psychiatric ward.* (Mary Wimberger Auslander)

Auslander also testified that because our society has a complete lack of tolerance for difference and staunchly denies the effects of poverty, the mental health system has become the repository for the victims of these attitudes. She also stated that as long as such attitudes prevail and their shortcomings and the consequences are ignored, a coercive, destructive, discriminatory, and lethal system of mental health care will continue. She testified that although more humane treatments are coming to the fore, the use of electroconvulsive therapy (ECT) is increasing because it is one of the treatments some insurance companies will reimburse.

Sharon Frieler, a member of the South Dakota PAIMI advisory council, testified about the effect on her cousin of ECT treatment.

> *My own cousin in Nebraska underwent many, many different treatments of ECT over a period of time. And what happens, in many cases, you lose parts of your life, your memories. And today, after years of treatments and being with psychiatrists, she is still depressed. She is still looking for those lost years.* (Sharon Frieler)

Further, ECT continues to be given against the expressed wishes of individuals.

> *The Center for Mental Health Services of the Federal Government did a review on the subject of electroshock human rights violations. It acknowledges that there are instances of illegal, forced electroshock against the expressed wishes of the subject. And we feel that's a real litmus test about empowerment. If the Federal Government is for empowerment of people with psychiatric labels, it will ban forced electroshock.* (David Oaks)

One method of increasing self-determination in psychiatric care is the use of advance directives (sometimes known as "living wills"). Through an advance directive, people can specify in advance what kinds of care they want, or don't want, at some future time in which they may be deemed incompetent to make treatment decisions. While originally envisioned as applying primarily to end-of-life care, advance directives also have applicability to people labeled with psychiatric disabilities, who are usually legally competent but who may experience periods when they are considered not to be. Xenia Williams, a mental health advocate from Vermont, testified concerning the use of advance directives for psychiatric care and the problems that she had experienced in attempting to implement the provisions of an advance directive in which she was named the substitute decision maker.

> *Since 1995, I have been an agent under a durable power of attorney for health care in the state of Vermont for [my friend]. She has not had her durable power of attorney honored by Vermont State Hospital or the Brattleborough Retreat, both of which receive federal monies. This is contrary to the Vermont statute for durable powers of attorney for health care and the federal Patients' Self-Determination Act, and it's discriminatory under ADA. People labeled with psychiatric disabilities should have their advance directives respected, the same as people who have lost capacity to make their own health care decisions because they were in a car crash and are in a coma. If you execute an advance directive, you should have the same rights to have it honored if your loss of capacity to make your own decisions is due to psychiatric situations as well as for other reasons of losing capacity. I'm a co-plaintiff with my friend in a lawsuit against Vermont State Hospital, to try to get enforcement of her advance directive. She has been discriminated against in being barred from having visitors at times. I have not been consulted about her care. They won't consult me; they just throw her back in the hospital, and then they feed her all kinds of drugs that are not good for her. They won't respect her wishes about which drugs she wants to take, and when, and other things that greatly affect her care. So, she's not getting her rights respected there.* (Xenia Williams)

Advance directives cannot necessarily prevent the administration of treatments people may choose not to have. A person may write an advance directive explicitly rejecting any form of psychiatric treatment, yet in every state such an individual can still be involuntarily committed.

People labeled with psychiatric disabilities often have other health problems that, when ignored, can lead to permanent disability and even death. William Brooks, the supervising attorney of the Mental Disability Law Clinic at Toro Law Center on Long Island, testified about an elderly woman who was left unattended in the bathroom of a state institution. When she fell off the toilet, the attendants did not believe that she was in pain, hoisted her up, and put her back into bed. After crying in pain all night, she was finally moved to a general medical hospital where an X ray revealed a broken hip. Since then, she has lost her ability to walk.

Anna Clege, a licensed practical nurse with 18 years of surgical experience and a native of Haiti, did not survive her stay in an institution. For Clege, language posed one barrier to her treatment. But a more dangerous barrier resulted in her death: Medical personnel ignored her physical symptoms. According to testimony from her sister, no one could communicate with Clege because no one on staff spoke her native language. On the morning following her admission, after staff heard a loud crash coming from her room, they found Clege on the floor. Although she was nonresponsive, lacked a radial pulse, and her blood pressure was inaudible, staff took no emergency measures. In fact, it was not until almost one hour after she collapsed that an EKG was administered and revealed that Clege had suffered a heart attack. Then, one hour and 10 minutes after she had collapsed, Clege was finally moved to medical emergency services, where she died 27 minutes later.

> *In her community, in addition to giving professional services, she always showed great generosity and hospitality to the ones in need. Our beloved sister was always there for all of us in our family. Her death created a tremendous hole in our family that leaves us with a lot of anger and frustration.* (Marie Clege)

Public Policy Recommendations

Congress should enact legislation that provides health insurance parity for voluntary mental health services for people labeled with psychiatric disabilities to the same extent that voluntary physical health treatment is provided. Involuntary treatment should not be covered in insurance parity legislation, since insurance coverage for physical health conditions does not mandate involuntary treatment. Legislation also should incorporate the following provisions:

- **Prohibit limits on the number of covered hospital days and outpatient visits.**
- **Eliminate copayments, coinsurance, and deductibles that are inconsistent with physical health portions of all policies.**
- **Eliminate provisions in Employee Retirement Income Security Act of 1974 that protect managed care organizations from liability.**
- **Amend the Mental Health Parity Act of 1996 to eliminate coverage for involuntary care and to eliminate the sunset provision.**
- **Eliminate the 50-employee threshold in the Mental Health Parity Act of 1996.**
- **Establish time limits for processing appeals of denied claims.**
- **Prohibit all forms of capitation and risk-sharing that induce managed care organizations and providers to cut services.**
- **Prohibit discrimination in supplemental health insurance policies.**

Institute closer oversight and monitoring of MCOs, Medicare, and Medicaid.

Congress should pursue legislative initiatives and regulatory changes that provide closer monitoring of MCOs. These initiatives should include uniform methods for maintaining expenditure data so that managed care company performance can be compared over time

and between companies. Expenditures and other critical data should be made available to the public.

Congress should initiate independent evaluations of privately managed care that analyze the number of persons using each service and the amount of services each person receives—as well as analysis of administrative versus service expenditures, expenditure trends, and consumer satisfaction.

Congress should fund research to monitor the impact of MCOs in Medicare and Medicaid mental health plans and the relationship between public and private mental health systems under diverse types of funding.

HCFA should exercise greater oversight and stricter enforcement of existing regulations to ensure coordination and accountability by its Medicare and Medicaid providers, as well as equity in the Medicaid program by eliminating discriminatory "special needs" plans that penalize people with severe disabilities and chronic conditions.

Proactive protection of patients' rights.

Congress should conduct public hearings on the experiences of people labeled with psychiatric disabilities with existing treatments.

Congress should enact a comprehensive patients' bill of rights that protects patients in all areas of health care but especially addresses the specific issues of people labeled with psychiatric disabilities.

Congress should mandate that, prior to receiving treatment, patients' advance directives are adhered to and informed consent forms clearly state due process rights in understandable terms.

Congress also should mandate that people labeled with psychiatric disabilities receive complete and current information concerning their diagnosis, treatment, and prognosis in terms that they can understand, and that these documents are signed without coercion

prior to receiving any treatment for a psychiatric condition at any facility that receives federal funds.

Congress also should establish a mandatory reporting system for this process and impose stiff penalties on facilities that fail to comply with these provisions.

Congress should further mandate that services be provided in a culturally competent manner that respects the ethnic and racial backgrounds of people labeled with psychiatric disabilities.

Considering the number of people labeled with psychiatric disabilities, current research funding for psychiatric conditions is inadequate. Significantly more federal research dollars are spent on health conditions that affect fewer people, due in part to powerful lobbying groups that exert significant influence over how federal research money is allocated.

Congress should allocate funding for research into safe alternative treatments for people labeled with psychiatric disabilities and ensure that people labeled with psychiatric disabilities are included in any review boards or policymaking decisions that result from research.

Congress also should fund a nationwide study on the status of mental health in the United States.

With the relaxing of FDA approval for new drugs, many drugs have received approval and have later been recalled by the FDA because of adverse reactions. In addition, much of today's drug testing is performed on adult male research subjects; therefore, it is difficult to determine the effects of such drugs on women and children. Drug testing standards should be revised to ensure that new drugs on the market are safe for use by women and children, minorities, and others.

DOJ should enforce existing provisions of ADA to remove barriers that prevent people labeled with psychiatric disabilities from communicating with their physicians, therapists, and service providers.

Congress should amend Medicaid and Medicare laws to ensure that health care professionals can communicate in a language that their clients understand.

Emergency medical training should be required for all staff who have direct contact with people labeled with psychiatric disabilities in institutions, residential treatment centers, and group homes that receive federal funds.

Medical and psychiatric personnel should receive training in addressing both physical and psychiatric conditions in people with disabilities.

The lack of culturally competent mental health services was also addressed by Sharon Frieler, a member of the South Dakota PAIMI advisory council.

> *The reality is not having readily available, culturally sensitive mental health services for the Native American, the largest minority group in our state. The reality is stigma that is exceptionally difficult to deal with, in an environment where the least bit of attention drawn to yourself, or forced up, let alone being associated with particular programs, will single you out, and say, "You are crazy." So, please don't lose the sense of these shared experiences you've heard here today. Deliberate on them. Think before you make your recommendations.* (Sharon Frieler)

Chapter 4

Criminal Justice

Neither law enforcement agencies nor the judicial and correctional systems have programs and policies in place to address the particular needs of people labeled with psychiatric disabilities while at the same time ensuring that they receive equal justice under law. When they are the victims of crime, testimony revealed that people labeled with psychiatric disabilities cannot rely on law enforcement agencies to protect *them*. The judicial system also fails them. Studies have found that rates of incarceration for people labeled with psychiatric disabilities are almost double the comparable rates in the general population. While it is often assumed that people labeled with psychiatric disabilities are in prison because they are particularly violent and dangerous, in fact, large numbers of prisoners with psychiatric disabilities are in prison for crimes that would not normally result in incarceration for nondisabled people. Inmates with psychiatric disabilities serve longer sentences than other prisoners and are less likely to receive voluntary treatment for their disabilities. Treatment in penal settings almost always consists of drugs, most often without any meaningful informed consent. In fact, imprisonment may actually exacerbate the symptoms of people labeled with psychiatric disabilities.

> *Law enforcement personnel often presume us to be without credibility in our complaints but assume us dangerous when complained against. Either way, our lives are held at very little worth.* (Laura Ziegler)

The Police Executive Research Forum (PERF), a national organization composed of chief executives from municipal, county, and state law enforcement agencies, offers a training curriculum and model policy that addresses police response to people labeled with psychiatric disabilities. PERF's trainer's guide, *Police Response to People with Mental Illness*, also covers the ADA and community policing approaches, including the voluntary and involuntary commitment process, arresting, and interviewing people with mental illness. However, as is typical of such training procedures, these materials were developed without input from people labeled with psychiatric disabilities. The training guide notes, "It is not the role of the police

officer to make the determination that a person should be committed." Testimony revealed, however, that police do not always adhere to this policy.

> *One woman described being locked out by her landlord. When she called the police, he told them, "It's just some nut who didn't pay her rent." And they took her to a psychiatric ward.* (Laura Ziegler)

When a person with a psychiatric disability is a victim of crime or has witnessed a crime, police should provide the same services they provide to all victims and witnesses. Unfortunately, this is not the case, according to Ziegler, a person with a psychiatric disability who has worked as a legal advocate in several states. She testified that the management of a building where she lived routinely broke into and entered apartments of tenants, many of whom had psychiatric histories. When she complained at the local precinct, she testified that the police clearly did not consider this an issue, since the perpetrator was a mental health agency and the victims were people labeled with psychiatric disabilities, who were not to be believed. When she consulted a legal agency, she was told it was a "gray area." She says the law is clear, but invoking the disability of the victims somehow made it gray. As a result, she says, people labeled with psychiatric disabilities who lived on this New York City block, which served as a crack and heroin supermarket and where occasional gunfire could be heard at night, could not expect the ordinary level of control and safety that comes with a locked door.

The PERF training model confirms that police are frequently unclear about the rights of people labeled with psychiatric disabilities:

> *Frequently, officers believe that only two dispositions are available: arrest or involuntary emergency evaluation. Although these are two formal dispositions, a number of informal dispositions also exist.* (Police Response to People with Mental Illness)

Ziegler recalled another incident in which one of her clients, who lived in an apartment run by a mental health agency, was attacked by a man who had threatened to kill her (the client) with a knife. He was not charged with any crime, an example of how people labeled with

psychiatric disabilities are frequently victimized both by criminals and by the criminal justice system that is supposed to protect them. When this same client, however, objected to the policy of the building's management of entering her apartment without her permission and stated that someone would get "knocked on their ass" the next time it happened, a staff person arranged for her to be psychiatrically committed because she was "violent."

Ziegler also testified about a family who called the police because they thought their son was having a psychiatric crisis.

> *When the police came, he was hit with a Tazer gun by an officer. What was he doing that invoked this response? He was crying.* (Laura Ziegler)

Betsy Pansa testified that when she called police to report her keys stolen, the policeman refused to take a report and made fun of her. When she asked him to leave her home, she was handcuffed and transported in the police car for a psychiatric evaluation.

Luz Marquez, associate director for outreach at the New York State Coalition Against Sexual Assault, testified that victims with disabilities are subject to unfair reporting requirements.

> *There is a New York state law that requires people who have cognitive disabilities to have a third person witness the actual assault.* (Luz Marquez)

Ziegler graphically depicted the vulnerability of people labeled with psychiatric disabilities in institutions.

> *When I was an advocate with the Long Island Protection and Advocacy Office, a client institutionalized at a state psychiatric center quoted a staff person as telling her, "You can't dial 911 in here." What would have happened if she had? The county police told me a staff person's verification would be required if a complaint came from a psychiatric ward. They did not explain how this would work if the alleged perpetrator was a staff person. On another occasion, at a conference on sexual assault and retraumatization, I questioned a panelist from the Queens D.A.'s*

office as to how they responded to complaints of a sexual assault emanating from DD or psychiatric centers. She replied that she couldn't answer my question because they didn't have a psychiatrist on the panel. This kind of discriminatory law enforcement effectively denies basic security to people who are extremely vulnerable to crimes of violence, including violence that is called "treatment." (Laura Ziegler)

Roy Neville, the president of the Alliance for the Mentally Ill of Schenectady, testified that jails and prison, rather than hospitals, are the new institutions for caring for mentally ill persons.

Bail is available to mentally ill defendants less often than other defendants. More mentally ill defendants spend longer in jail detention than other prisoners. Mentally ill prisoners spend a larger portion of their sentence in prison than other prisoners, on average. They are more often denied parole than the others. (Roy Neville)

The Center for Mental Health Services (CMHS) reports "the sheer magnitude of people with serious psychiatric disorders in jails is staggering." In July 1998, the Department of Justice's Bureau of Justice Statistics (BJS) reported that an estimated 284,800 mentally ill offenders were held in the nation's state and federal prisons and local jails in mid-1998. Another 547,800 mentally ill people were on probation in the community.

CMHS reports that on an average day, 9 percent of men and 18.5 percent of women entering local jails have a history of serious mental illness—rates two to three times higher than the general population. An estimated 700,000 new admissions annually to jails are individuals with acute and severe mental illness, compared with 731,510 people who are admitted annually to inpatient psychiatric facilities.

The local jail persistently remains one of the community settings where people labeled with psychiatric disabilities reside, however briefly, during the course of their long illness. Most often, these are people whose only crimes are minor offenses—public nuisances associated with homelessness (in Los Angeles, over 70

percent of people with mental illness have been arrested), or confusion, often mistaken for public drunkenness. (Mental Health, United States, 1998, CMHS)

CMHS estimates the prevalence of serious mental illness (SMI) to be as high as 57 percent among the 1.1 million adult residents of correctional institutions. In some communities, arrests may constitute "mercy bookings" to remove people from the streets because the mental health services they need are inaccessible or unavailable because of scarce resources. Whether the people so arrested consider it an act of mercy is questionable.

BJS's *Mental Health and Treatment of Inmates and Probationers* reports that, on average, inmates with psychiatric disabilities were expected to serve 103 months in state prisons before their release—15 months longer than other inmates.

The trauma of incarceration, regardless of the length of time, may exacerbate their symptoms and put people labeled with psychiatric disabilities at risk for suicide. Between 75 and 95 percent of people who commit suicide in jails or in prisons have a mental disability, according to information provided in *Mental Health, United States, 1998.*

In criminal courts, mentally ill persons don't receive fair treatment in this era of "let's get tough on crime." They receive an uneven defense in court from public defenders who may not understand mental illness...and are too overworked to deal with each case sufficiently. Plea bargains and trials result in jail and prison terms more severe on the average than for other defendants. (Roy Neville)

In correctional facilities, services differ from locality to locality. In 1997, for example, the Cook County, Illinois, jail provided services to only 37 percent of men and 23.5 percent of women who needed them. Such services usually consist of administration of psychiatric drugs rather than counseling or therapy.

Cliff Zucker, the executive director of Disability Advocates, Inc., an Albany, New York, P&A organization, cited the example of a prisoner who went for days without treatment because his medical records did not accompany him when he was transferred from one correctional facility to another. It took the intervention of the P&A before the inmate received his

medication. In the past, prisoners with mental illness received help from prisoners' legal services, but federal funding was eliminated for this program.

The problems in the criminal justice system need to be addressed systematically in ways that include the views of people labeled with psychiatric disabilities and their advocates. Excluding these viewpoints will perpetuate many of the mistakes of the past.

Public Policy Recommendations

Institute mandatory training for all personnel who work in law enforcement; the judicial, penal, parole, and probation systems; and victim assistance programs on the requirements of ADA and other laws that protect the civil and human rights of people labeled with psychiatric disabilities.

Mandatory training should be required for all law enforcement, criminal justice, and correctional personnel, including prison guards and probation officers, as well as people working in victim assistance programs. Training should be coordinated with PERF, DOJ's Office of Victims of Crime, and the National GAINS Center.

The latter, established in September 1995, provides technical assistance to states, localities, and criminal justice and provider organizations that are in the process of developing or implementing services to people with co-occurring psychiatric disabilities and substance abuse disorders at all stages of the justice system—law enforcement, jails, prisons, probation, and parole.

DOJ should ensure that these organizations remove all physical and attitudinal barriers and that the programs are accessible to people labeled with psychiatric disabilities.

People labeled with psychiatric disabilities should be included in all policy and program development, decision making, and service delivery from the time of the crime through case disposition and beyond.

In addition, people labeled with psychiatric disabilities should be recruited and trained to become volunteers and paid staff members in criminal justice programs, especially in system-based or private victim assistance programs.

Increase involvement in protecting the rights of people labeled with psychiatric disabilities who are defendants in courts and inmates of state and local corrections systems.

People labeled with psychiatric disabilities should be an integral part of all policymaking that addresses prevention of crimes by people labeled with psychiatric disabilities and how to best meet the needs of offenders.

Chapter 5

I Had to Give My Child Away Because She Has a Disability

While only a few witnesses addressed the question of children with psychiatric disabilities, it is clear from testimony that many of the same problems affecting the adult mental health system carry over into the children's system as well. Witnesses testified to a lack of parental involvement in treatment decisions; the requirement that, in many cases, parents relinquish custody to the state in order to obtain services; poor interface between the educational and mental health systems; problems with obtaining and retaining SSI benefits; and a host of other difficulties.

The National Institute of Mental Health (NIMH) reports that 1 in 10 children and adolescents have an emotional disturbance severe enough to cause some level of impairment. In 1996, suicide was the third leading cause of death among 15- to 24-year-olds, and the fourth leading cause of death in 10- to 14-year-olds. (It should be noted that "severe emotional disturbance" is the term used by the Federal Government for those under 18; people over 18 are designated as "mentally ill.")

The number of children receiving services in private residential treatment facilities more than doubled between 1969 and 1994. Children with psychiatric disabilities are more likely than all other children with disabilities to receive educational services in residential settings or separate classrooms. They fail more courses, earn lower grade point averages, miss more days of school, and are retained at grade more than students with other disabilities. Fifty-five percent leave school before graduating.

Because eligibility for Medicaid and other public health programs differs from state to state, many children with psychiatric disabilities never receive appropriate treatment. In response, some parents even relinquish custody of their children, hoping that as wards of the state, they will receive better services and treatment. But frequently, treatment for these children—and all children with psychiatric disabilities—is provided in state and privately operated institutions, or even juvenile correctional facilities, where they may endure pain, abuse,

and torture. The recent emphasis on sending juvenile offenders to "boot camp" programs has resulted in several underpublicized deaths in the past year alone.

BJS reports that offenders with severe emotional disorders who were incarcerated or on probation reported higher rates of prior physical and sexual abuse and higher rates of alcohol and drug abuse by a parent or guardian while they were growing up. More than 40 percent of inmates with psychiatric disabilities said their parents had abused alcohol or drugs. More than half said a parent, brother, or sister had also been in prison or jail.

At school and in their communities, children with severe emotional disturbance suffer the anguish and pain that come with the stigma of living with a psychiatric disability. For a child, this can be especially damaging.

Families of children with severe emotional disturbances often lack the financial resources to provide adequate treatment, and for parents with their own psychiatric disabilities, this can be even more difficult. Susan Mikolik testified that she, her husband, and two of their children have psychiatric disabilities. Both she and her husband are professionals who work full-time. However, Mikolik states:

> *The impact that this overwhelming volume of afflictions creates on our family's functioning is devastating. The two primary areas that create additional burdens for us to deal with are financial/insurance issues and school issues.* (Susan Mikolik)

Mikolik also testified that although her son is medically qualified, he has been denied SSI benefits because of the family's income, since the formula for calculating assets does not include expenses, which can at times amount to $500 a week for psychiatric treatment for her family.

Carol Wilson of Family Voices, a national grassroots organization that speaks on behalf of children with special health care needs, and the parent of a child with severe emotional disturbances, testified that children with severe emotional disturbances were unfairly singled out when stricter eligibility criteria were required for SSI benefits for children with disabilities.

Children receiving SSI and Medicaid were cut, and all benefits ceased, and the large portion of those were children with serious emotional disturbances, because there's not a test you can run at a local hospital that's going to show you what this child has. (Carol Wilson)

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996, commonly referred to as Welfare Reform, made eligibility for childhood SSI more restrictive. After the law was enacted, SSA reviewed the existing eligibility of some 288,000 children against the new standards. In response to numerous complaints that children would be hurt by these cuts, SSA reduced the number of cases it would review and agreed to reevaluate the entire process.

SSA estimates that approximately 100,000 children eventually will lose SSI benefits as a result of Welfare Reform. Although many children lost SSI, the Balanced Budget Act of 1997 included a provision that ensured that those children would continue to remain eligible for Medicaid.

The issues that you've heard today about managed care taking over, insurance discrimination [is] a big part of it. Managed care [is] taking over. Medicaid is a concern because managed care does not understand the early and periodic screening, diagnosis, and treatment portion, which is a mandatory Medicaid provision for children, and that these services must be provided if they're medically necessary. (Carol Wilson)

Wilson contends that MCOs do not understand how Medicaid provisions apply to children with psychiatric disabilities. The result is a very fragmented delivery of treatment, and children with psychiatric disabilities frequently do not receive what they need.

Wilson testified, and studies confirm, that, overall, children have lost insurance at a much higher rate than adults. To offset this, the Balanced Budget Act of 1997 also created the State Children's Health Insurance Program (SCHIP) under Title XXI of the Social Security Act. SCHIP enables all states, the District of Columbia, and five territories to initiate and expand

health insurance coverage for uninsured children. In FY 1998, Congress allocated $4.275 billion for the program.

> *Unfortunately, not one single state has implemented mental health parity in their state children's health insurance program. And that's a concern. What happens? What is the result? Families such as mine are told to give up custody of their children to the states in order to receive mental health treatments and services, and those services usually aren't provided. The children are put in foster care; they fall through the cracks. The other option presented is to declare your child an ungovernable child and have them put in the juvenile justice system.* (Carol Wilson)

According to the GAO, as of April 1, 1999, HCFA had approved 51 state plans for SCHIP; 2 were under review; and 3 had not been submitted. Some 982,000 children were enrolled in the new program. Under SCHIP, a state has the choice of expanding Medicaid; establishing a separate stand-alone program that can include cost-sharing and allows the state to adopt a benefit package that meets one of several employer-based benchmarks; or combining these two approaches. To date, most states have chosen to expand their Medicaid programs.

For its report, GAO sampled 15 states. In eight states with the SCHIP stand-alone component, mental health, prescription drugs, vision, hearing, and dental coverage were *optional* benefits that, with the exception of prescription drugs, placed limits on the duration of treatment allowed or on the amount of services covered. In those eight states, optional mental health benefits place limits on the number of days for inpatient treatment and the number of outpatient visits.

> *For the majority of children, such benefit limitations are not likely to result in inadequate diagnosis and treatment. Children with special needs, however, may not receive the full range of services that their conditions might warrant.* (Children's Health Insurance Program: State Implementation Approaches Are Evolving, GAO May 1999.)

Susan Mikolik testified that school issues for families with young children with psychiatric disabilities "are tremendous." She asserted that children with severe emotional disturbance (SED) and those with severe behavior handicaps (SBH) are being placed in combined classes to save money. Mikolik acknowledges that some children may carry dual diagnoses, but she believes it is inappropriate to place a SED child—with little or no SBH tendencies—into an SBH class. She states that *all* children falling into this category are not receiving a free, appropriate public education as required by law.

The 20th Annual Report to Congress submitted by the U.S. Department of Education in 1998 reports that some 447,426 children with emotional disturbances ages six and older were served under the Individuals with Disabilities Education Act (IDEA) during the 1996–97 school year. Over the past five years, the overall number of children served under IDEA has increased, but the number of certified special education teachers has not. Convincing evidence now exists that there is a substantial, chronic national shortage of special education teachers who are fully certified in their positions.

The IDEA Amendments of 1997 strengthened IDEA to include an appropriate evaluation, development of an individualized education program (IEP), education provided in the least restrictive environment (LRE), parent and student participation in decision making, and procedural safeguards to protect the rights of parents and their child with a disability. The law now specifically requires that a free, appropriate public education also must be made available to children who are suspended or expelled.

According to *The 20th Annual Report*, the majority of students with emotional disturbances, however, continue to be served in separate classes from other students. Even when they are placed in regular classes, research suggests that many of these students and their teachers do not currently receive the supports that they need to succeed.

Testimony revealed that their issues are generally ignored, because children with psychiatric disabilities are dealt with as discipline problems. When treatment and services are not available, some parents are left with no choice but to relinquish custody of their children to the state.

In 1994, SAMHSA reports that 26,493 children received treatment at residential centers for emotionally disturbed children—a number that more than doubled since 1969, when only 13,489 children were treated in such facilities. In fact, Department of Education data, based on a December 1, 1995, survey and updated on September 1, 1997, indicated that children with emotional disturbances were almost twice as likely to receive services under IDEA in public or private residential facilities than any other group of children with disabilities.

Once institutionalized, children with psychiatric disabilities are subjected to the same abuses as their adult peers. Isolated in institutions, children are unwilling or unable to report abuse, and in some instances the staff may cover up incidents as previously reported.

If children don't receive treatment in residential facilities, they may end up in jail. As many as 14,904 received IDEA services in correctional facilities during the 1995–96 school year. Wilson asserts that approximately 60 percent of the children in the juvenile justice system have serious emotional disturbances but do not receive adequate treatment. Some children who enter a juvenile correctional facility never leave alive, as has happened in some boot camp programs.

According to a report in the May 21, 1999, issue of *The Washington Post*, 16-year-old Wallace Wesley Dandridge, who was described in the article as "an emotionally turbulent, mentally retarded youth," was found in respiratory distress, lying face-down on a steel bunk in his cell at the Oak Ridge Juvenile Correctional Center in suburban Richmond, Virginia. His hands were in standard-issue leather restraints and his pulse was nearly gone when a state trooper arrived to charge the young man with assaulting an officer at the juvenile facility. Unfortunately, an emergency tracheotomy that failed to save his life also may have destroyed any evidence that he was possibly choked or strangled.

On a happier note, Carol Wilson's son obtained employment through vocational rehabilitation and has been out of the hospital for 11 months, which is the longest time he has ever been able to stay out in the past four years.

He's happy, he's in the community, and he is doing well. But it was a hard-fought battle, and 86 percent of the children in my state aren't receiving any services. We have to look at these children. Putting them in juvenile justice is not the answer. And parents giving up custody of their children is not an answer. It's a violation of my civil rights that I have to give my child away because he has a disability. (Carol Wilson)

Public Policy Recommendations

Many children are given drugs that have serious and long-lasting damaging side effects, including other types of mental illness. Safer treatments must be developed. Particular attention should be paid to dramatic increases in the past five years in the number of children given Ritalin and other stimulant drugs for "hyperactivity."

Ensure that SSA's clinical study directed at evaluating the most effective approach for assessing functioning in some SSI children applicants addresses the unique needs of children with severe emotional disturbances. SSA benefit eligibility rules should be amended to include all extenuating financial and other circumstances that may have an impact on a determination of SSI benefits involving people labeled with psychiatric disabilities.

HCFA should enforce Medicaid's existing early and periodic screening, diagnosis, and treatment provisions. HCFA should issue a policy statement to state Medicaid officials emphasizing that Medicaid provisions apply to children with severe emotional disturbances, and that denial or failure to provide these services will result in loss of Medicaid funding.

In coordination with the Health Resources and Services Administration and other federal agencies, HCFA should closely monitor SCHIP to ensure that children with severe emotional disturbances are receiving services through the program. Federal funding should be withheld from states that exclude or limit SCHIP mental health services.

The hearings should identify barriers to treatment, explore how children are used in research, and why so many children with severe emotional disturbances are receiving services under IDEA in separate classes or in residential facilities.

The U.S. Department of Education should monitor and enforce existing provisions of IDEA and ensure that children with severe emotional disturbances are receiving their education in the most appropriate, integrated settings.

Congress should fund aggressive education and outreach programs about the rights of children with severe emotional disturbances under IDEA, other laws, and available services and resources.

Congress should earmark funds for additional fully certified special education teachers to eliminate the current and projected shortage.

Federally funded programs providing treatment and services should require parents and/or caretakers to sign informed consent forms that clearly state the available treatment, potential risks, and alternatives. Stiff penalties should be levied against service providers who use coercion or provide inaccurate information or fail to obtain signed informed consent forms.

Congress should appropriate funding for additional psychologists and social workers to work in schools with children with severe emotional disturbances. Services provided in schools also should be expanded to include early intervention and treatment for children at risk and to provide appropriate services to children with severe emotional disturbances and/or substance abuse and behavioral problems. This funding could also provide in-school peer support groups for children with severe emotional disturbances and those recovering from substance abuse.

Congress should appropriate funding for community- and home-based treatment for children with severe emotional disturbances and their parents.

Multi-systemic therapy (MST), for example, is a mental health service that focuses on changing how youth function in their natural settings—at home, in school, and in their neighborhood. It is designed to promote positive social behavior while decreasing negative behaviors, including delinquency and substance abuse. Therapists work in the home to strengthen the ability of parents or caretakers to raise children with complex problems. In a series of random trials, NIMH reports that MTS has proven effective in reducing long-term rates of rearrests by serious juvenile offenders by 20 to 70 percent.

Chapter 6

A Zillion Forms and Still No Civil Rights

People labeled with psychiatric disabilities have little or no control over existing federal programs and policies that directly affect their lives, because their opinions are not valued or are ignored. For example, the June 7, 1999, White House Conference on Mental Health was dominated by people without psychiatric disabilities, nonconsumer-controlled mental health organizations, and the pharmaceutical industry. By virtue of their exclusion, the voices of people labeled with psychiatric disabilities were silenced when they should have had the most impact, especially when national attention was focused on policy that directly affects them.

> *I admire my peers who struggle valiantly to recover what they have lost, to resume normal lives in the face of psychiatric labeling. Their very being has been invalidated by psychiatric diagnosis. In many cases, their physical existence is now dependent upon the mental illness industry.* (Angela Cerio)

> *I believe that the label of mental illness is the beginning of human rights violations.* (Debbie Whittle)

George Ebert, an advocate with the Mental Patients Liberation Alliance in Syracuse, New York, testified that when he was labeled a paranoid schizophrenic, "It gave them the right to actually disable me with involuntary confinement—solitary confinement, forced drugging, and shock treatments."

Daniel Fisher, a psychiatrist, testified that some states, such as Massachusetts, had to pass legislation to ensure the human rights of people in institutions who are labeled with psychiatric disabilities, such as the right to make a phone call or have visitors, legislation that would not be necessary if people labeled with psychiatric disabilities did not lose their ordinary citizenship rights. It is important to note that both in institutions and in community facilities, rights are referred to as "privileges" that must be earned, generally by compliance with treatment. Such so-called "privileges" as using the telephone or having access to fresh air must be recognized as basic rights that may not be infringed. Just as it would be intolerable and unacceptable for

people to lose their rights when they enter a hospital for medical treatment or surgery, such policies should be similarly unacceptable in psychiatric facilities.

Many of the federal programs available to people labeled with psychiatric disabilities work against self-determination and wellness. All people with disabilities who want to return to the workforce face barriers—many of them were addressed in *Removing Barriers to Work*, NCD's 1997 report. People labeled with psychiatric disabilities, however, encounter some unique barriers, and the stigma associated with their disabilities is the most egregious. Testimony revealed that many people labeled with psychiatric disabilities also are homeless and cannot access vocational services, and that people who *are* employed and acquire psychiatric disabilities often are refused accommodations. Worse, a provision in one federal law allows some people labeled with psychiatric disabilities to work for little or no compensation, when such work is part of a "therapeutic program."

> *Patients are routinely coerced into forfeiting their rights in the name of treatment, and, in general, the system is structured to render consent meaningless. The hospital has a canteen overseen by therapeutic activity staff that sells light meals and beverages. If it was recommended that you work there, you could not refuse. Refusing to participate in any treatment recommendation immediately halted your privileges, including passes. We were not paid for working at the canteen, although it made money. It was considered hostile to mention the similarity between this and indentured servitude.* (Diana Rickard)

When people labeled with psychiatric disabilities attempt to work and apply for employment, they frequently encounter discrimination or are offered low-paying positions even if they have extensive work histories at responsible jobs. Further, SSA regulations limit the number of hours they can work before losing benefits and medical coverage.

> *The truth is that my success is not a miracle but a lot of hard work—harder than it needs to be. The work incentives in place now rarely produce a person like me. My brothers and sisters struggle daily. They want to be productive, but they're stuck. Why? Because no one knows how to gradually get out of the system.* (Vicki Smith)

Bernice Loschen testified about another barrier facing people labeled with psychiatric disabilities when they seek employment.

> *Because when you work, if you have a co-pay...you have to pay a co-pay on your medicines. You don't make enough to pay for your medicines. You don't make enough to pay for your medical care.* (Bernice Loschen)

Effective July 1, 1999, people with some disabilities who receive SSDI now can earn as much as $700 without losing benefits. This is the first increase in 10 years. But people who are blind can earn as much as $1,100 each month before losing their benefits. Several people testified that this inequality is unfair.

> *Return-to-work and employment programs contain disincentives that force persons willing to work to remain on entitlement programs.* (Sharon Frieler)

People who receive SSI are penalized for anything that they earn over $65 in one month. NCD heard numerous calls for reforms of SSA and welfare regulations to promote, enhance, and support employment for people with disabilities.

Lucy Kim, the administrative coordinator at the Center for Urban Community Services in New York, who herself successfully transitioned from SSI/SSDI to work, recommended that health benefits continue until an individual obtains employment that provides full medical coverage, adding that the length of time could vary, depending on how long it takes to acquire medical benefits. Kim also recommended that employment and vocational services be conveniently located in shelters and community-based programs where other services are provided, noting that she was inspired to seek employment by a sign she read in a homeless shelter. She also testified that day treatment should focus more on employment and meaningful activity, and noted the many barriers that prevent people labeled with psychiatric disabilities from returning to work successfully.

> *The internal obstacles are low self-esteem, lack of work experience, fear of maintaining psychiatric stability while under an enormous amount of stress starting a new job, and fear of losing benefits. Some of the external obstacles are losing*

Medicaid, which enabled me to function. And, I had to lie, basically, to keep my Medicaid benefits in the transitional period. And also, I feel the SSI two-for-one earning scale is a disincentive. (Lucy Kim)

People who are both homeless and mentally ill face numerous barriers in obtaining services that help them obtain permanent housing and work. The Task Force on Homelessness described barriers to services in its 1992 report:

People who are severely mentally ill and homeless require an extremely broad array of resources and services—including housing, food, clothing, health and mental health care, treatment of alcohol and other drug abuse, and psychosocial and vocational rehabilitation. Yet in more communities of any size, they must negotiate an extraordinarily complex and disconnected set of bureaucracies to obtain access to these services. (Outcasts on Main Street: Report of the Federal Task Force on Homelessness and Severe Mental Illness, DHHS, 1992.)

The Task Force recommends that service providers break traditional molds of providing services by meeting and engaging homeless people on their own terms and on their own turf.

Despite the many barriers, however, some people persevere and succeed.

I filled out a zillion forms, and so did my boss, and so did my former mental health providers, but I'm completely off the system, and glad to be. (Xenia Williams)

Ellen Lawson, a P&A attorney in Buffalo, testified that the current body of work incentives and other rules governing how employment affects Social Security benefits is so complex that very few SSA personnel truly understand them. Lawson recommended rules that are easier for SSA personnel to administer and easily understood by recipients and service providers. She also suggested that Social Security and SSI rules be made uniform.

There should be a parallel set of rules for both Social Security and SSI. Often, in reading through the provisions, I wonder why there are such profound differences, and that provisions are so much more liberal in some cases for SSI, a poverty-based

program. The rules should apply equally regardless of disability, apply equally to applicants and recipients, and apply equally regardless of what state a person resides in. Uniformity would eliminate much of the current complexity. (Ellen Lawson)

One advocate questioned why only 243 Plans for Achieving Self Sufficiency (PASS), a Social Security work incentive program, were written in the entire country in 1997. A PASS allows people with disabilities who are SSI recipients to set aside income and/or resources for a specified period of time to achieve a work goal. Because writing a plan is so complex, and many providers and Social Security workers are unfamiliar with them, PASS remains an extremely underutilized method of helping people return to work.

Discrimination in hiring against people labeled with psychiatric disabilities continues to be a pervasive problem. On June 4, 1999, President Clinton directed OPM to ensure that the Federal Government has the same hiring and promotion standards for people labeled with psychiatric disabilities as it has for people with other disabilities. Although this directive was a step in the right direction, it does not guarantee that the numbers of people labeled with psychiatric disabilities in the federal workforce will increase. In general, federal employment of people with disabilities has never achieved employment objectives.

Section 501 of the Rehabilitation Act of 1973 (P.L. 93-112, as amended by P.L. 99-5061) requires agencies, departments, and instrumentalities of the executive branch of the Federal Government to submit to the Equal Employment Opportunity Commission (EEOC) annual accomplishment reports and affirmative action program plan updates for the hiring, placement, and advancement of people with disabilities. The Federal Government defines targeted disabilities as "deafness, blindness, missing extremities, partial paralysis, convulsive disorders, mental retardation, mental illness, and distortion of limbs and/or spine." In FY 1997, EEOC reports that people with severe disabilities represented only 1.16 percent of the total federal workforce—a figure far below the estimated 5.95 percent availability of people in the United States with targeted disabilities who were of workforce age and seeking employment.

Pam Olson, a mental health professional who also has experienced recurrent mental illness, testified that she naively expected ADA to protect her when she became ill. At the time she informed her employer about her depression, she had more than 20 years experience as a school psychologist and a classroom teacher and had always received positive evaluations. Olson testified that she allowed her employer to contact her therapist, assuming this would help her obtain the accommodations she needed. Instead, she was subjected to harassment, falsely accused of dishonesty, stalking, and intimidating others—none of which occurred. Her employer had rated her unsatisfactory in many areas, which were actually symptoms of her illness.

When her internal complaints of discrimination were ignored, Olsen filed suit in 1995. The court determined that she was not disabled and that she did not qualify for protection under ADA, because she was still able to perform her job—despite her unsatisfactory rating. The court also determined that ADA did not apply, because she could perform other jobs in a number of other areas. She states ADA provides little to no protection for those with psychiatric conditions, and that employers and the courts are unfamiliar with the law.

> *I believe the courts, at this time, are perpetuating the stigmas and misunderstandings of mental illness rather than combating them. The burden of proof that must be met to prove mental disability under ADA sets an impossible standard.* (Pam Olson)

There is also a continuing problem of people who are forced to work with little or no compensation. In all 50 states, many institutions use patient workers to perform tasks for no salary or at a salary below the minimum wage. Sheltered workshops in the community also routinely pay less than minimum wage. The Fair Labor Standards Act (FLSA) simply requires an employer to obtain a subminimum wage certificate from the regional office of the U.S. Department of Labor (DOL) Wage and Hour Division. Data obtained from DOL on June 21, 1999, reveal that some 511 public and private institutions obtained certificates to use 27,395 people as patient workers—a marked increase since 1996, when only 374 institutions used 14,482 patient workers. This increase may be attributed to the fact that institutions no longer are required to report the total number of hours worked by patient workers, or financial information such as wages. As a result, it is difficult for DOL to monitor FLSA violations.

Sheltered workshops, transitional employment programs, programs that use job coaches, and similar programs commonly treat people labeled with psychiatric disabilities differently from other workers, particularly in the area of wages. Real work, in integrated settings with the same wages and benefits as nondisabled workers, remains tantalizingly out of reach for many participants in "work readiness" programs.

Perhaps the most egregious violations against people labeled with psychiatric disabilities occur in the area of civil rights. Despite the provisions of ADA and other civil rights laws and the protections afforded under the due process and equal protection clauses of the U.S. Constitution, people testifying describe incident after incident in which the civil rights of people labeled with psychiatric disabilities were repeatedly violated or disregarded.

> *Right now, in this country and virtually every country in the world...by virtue of our diagnosis, by virtue of our label, we don't have the same rights that other people have. We can be put into institutions because a doctor says we need to be there. There's usually some sort of court procedure, but it's not real due process. And until that changes, we're going to continue to be second-class citizens.* (Judi Chamberlin)

Several laws address various aspects of civil rights protections for people labeled with psychiatric disabilities. CRIPA authorizes the U.S. Attorney General to investigate conditions of confinement at state and local government institutions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, and publicly operated nursing homes, as well as institutions for people with psychiatric and developmental disabilities. This law covers systemic conditions that could seriously jeopardize the health and safety of residents in institutions. Isolated incidents of abuse cannot be investigated under CRIPA.

The Developmental Disabilities Assistance and Bill of Rights Act of 1975 (the DD Act) and the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (PAIMI) were enacted to protect the human and civil rights of people with disabilities in institutions. The DD Act and PAIMI provide a congressionally mandated nationwide network of protection and advocacy services. In 1994, Congress provided full funding for the Protection and Advocacy for Individual Rights (PAIR) program, which was established in 1978 but never funded under the

Rehabilitation Act. The PAIR program provides P&A services to all people with disabilities who are *not* in institutions. However, many PAIMI programs have not aggressively pursued their original mandate. One such program, for example, claimed to have "served" 66 persons in a six-month period (the mere providing of a program brochure being counted as providing a service). The level of activism of P&A programs continues to vary dramatically among the states.

Unlike other Americans, many people labeled with psychiatric disabilities are denied their civil rights because federal laws fail to protect them. Involuntary commitment to a mental health facility can be ordered by a court, a physician, or a legally authorized mental health practitioner, depending on local laws, which vary from jurisdiction to jurisdiction. Police are often called upon to pick up people labeled with psychiatric disabilities for involuntary commitment. This is seen by many people labeled with psychiatric disabilities as a denial of their basic citizenship rights.

> *I knew she and I did not live in the United States, and we're not citizens of that country. We lived in the gray area where we could be arrested and incarcerated in all but name for being dangerous.* (Laura Ziegler)

> *Because of a few dramatic episodes sometimes involving persons with a psychiatric diagnosis, all of us who have a diagnosis are made to face forfeit of our civil liberties.* (Joseph Walsh)

Joe Young testified that when one of his institutionalized clients called 911 for help, he was promptly moved from a cottage and full grounds privileges into a locked ward and involuntarily administered Lithium. When deaths and incidents of abuse occur in institutions, P&A organizations have difficulty accessing records about the incidents. Essentially, many institutions self-investigate crimes and may even compromise evidence that could be used in criminal proceedings.

> *These are some of the reasons that these institutions have to be monitored, and the Federal Government should stop subsidizing the unnecessary confinement of persons in the institutions.* (Joe Young)

According to information provided by DOJ, as of June 15, 1999, DOJ's Special Litigation Section is investigating mental health services in 65 health care and correctional facilities. It is also monitoring remedial settlements involving mental health services in 128 health care and correction facilities and hundreds of community placements from facilities under court orders. DOJ states that since 1993 the Section has investigated mental health services and monitored remedial settlements to improve mental health services in over 300 health care and correctional facilities in more than 42 states, the District of Columbia, the Commonwealth of Puerto Rico, and the Territory of Guam.

> *As a result of the Section's efforts, tens of thousands of persons with mental illness are now receiving adequate services.* (Special Litigation Section, U.S. Department of Justice, June 25, 1999.)

Nonetheless, NCD heard again and again how helpless and powerless people felt in treatment settings.

> *Patients are routinely coerced into forfeiting their rights in the name of treatment and, in general, the system is structured to render consent meaningless.* (Diana Rickard)

Walsh testified that inpatient commitment in New York State is achieved with the systematic participation of New York State Mental Hygiene Legal Services (MHLS).

> *MHLS, originally intended as a legal advocacy service, has become a rubber stamp for doctors' orders for involuntary commitment. First, the doctor requests a judge to impose an involuntary commitment order. Invariably, a judge grants the doctor's request. When advocacy is requested by the subject of the commitment order, MHLS responds that they cannot or will not challenge the judge's order. The judge won't challenge the doctor; MHLS won't challenge the judge. Doctors' orders for commitment [are] facilitated with the appearance of due process. The state has therefore created an apparatus to create the illusion of due process.* (Joseph Walsh)

Like other elements of the mental health system, advocacy services and rights protection are also implemented without major participation by people labeled with psychiatric disabilities themselves, leading to an often paternalistic attitude of "best interests" rather than paying attention to what people want for themselves. Advocacy services need to become accountable to the people they serve.

Virtually nothing has been done at the local or federal level to protect people with disabilities who are victimized in institutions and in their communities.

> *Until recently, the crime victims' movement has not worked systematically to identify issues and challenges involved in responding more effectively to victims with disabilities. Improving service delivery to people with disabilities must become a priority, because the crime victims' rights movement is founded on the premise that every crime victim deserves fundamental justice and comprehensive, quality services.* (U.S. DOJ Office for Victims of Crime, *OVC Bulletin: Working with Victims of Crime with Disabilities,* September 1998.)

The *OVC Bulletin* cites a survey by Dick Sobsey, R.N., Ed.D., indicating that 48.1 percent of the perpetrators of sexual abuse against people with disabilities had gained access to their victims through disability services. *OVC Bulletin* notes that people who are victimized are vulnerable to exacerbated suffering. Also, most victims will experience a sense of shock, disbelief, or denial that the crime occurred, often followed by cataclysmic emotions, including fear, anger, confusion, guilt, humiliation, and grief. People with disabilities, however, may have intensified reactions because they may already feel stigmatized and often have low self-esteem due to societal attitudes.

Unlike most *OVC Bulletins* focusing on special categories of victims, *Working with Victims of Crime with Disabilities* offers no authoritative "census" describing the numbers and characteristics of the victim population under review, because—again—no authoritative data currently exist. The *Bulletin* does cite several studies, including one published in the *American Journal of Psychiatry*, that revealed that 81 percent of psychiatric inpatients had been physically or sexually assaulted at some point in their lives. The Colorado Department of Health estimates

that upward of 85 percent of women with disabilities are victims of domestic abuse, in comparison with, on average, 25 to 50 percent of the general population. These statistics, which have been replicated in many states, call into question the "brain disease" model of mental illness, indicating that trauma, not disordered brain chemistry, explains many emotional reactions.

Tina Minckowitz, a representative of the Brooklyn Mental Hygiene Court Monitoring Project, expressed concern that due process hearings prior to involuntary commitment do not protect people's rights.

> *In New York, as in probably most other states now, they have to—they're supposed to—go through a court hearing before they can drug you by force, unless they consider it an emergency. And basically 90 percent of the time—99 percent of the time—the psychiatrists get to do what they want. So the hearings are not giving people protection against forced drugging.* (Tina Minckowitz)

Minckowitz testified that emergency forced drugging is extremely abused and that people are force-drugged in institutions because they speak up for their rights or because they speak up when they see another patient or inmate being abused.

According to testimony, funding and resource limitations are leaving vulnerable people labeled with psychiatric disabilities unprotected. Lawson, who has worked in the PAIMI program for 12 years, testified that more people are eligible for PAIMI services, but current funding levels prohibit this. As a part-time attorney who is assisted by two other part-time staff, she must cover a 15-county region in western New York, encompassing two cities and a number of rural areas. Because of such staffing and funding limitations, Lawson stated that a three-hour drive to interview one client is not unusual. If funding were higher, she testified, they could move quickly and expediently to protect the rights of their clients.

Psychiatrist and psychiatric survivor Daniel Fisher testified that the label of mental illness should not deprive people of their fundamental constitutional rights.

What happens in a country, as it happened in Nazi Germany, when people who are labeled as fundamentally different and flawed, as our biological psychiatry model does, the next step can be the deprivation of rights, forced treatment, and gradual extermination. I hope that we recognize that it could happen in any country. We should make sure that there's due process of law protection, so if somebody is hospitalized or in the psychiatric system, they have access to legal advocates. (Daniel Fisher)

People labeled with psychiatric disabilities can be subjected to research with little legal oversight. Written testimony submitted by Cliff Zucker, the executive director of Disability Advocates, Incorporated (DAI), which provides P&A services for persons with psychiatric disabilities in New York State, outlined his agency's court challenges to nontherapeutic and risky experiments conducted in state psychiatric facilities on those incapable of giving informed consent. The result has been an invalidation by the courts of research regulations of the state Office of Mental Health and a move by the state Department of Health to convene an advisory committee to devise new guidelines for non-federally funded psychiatric research.

Zucker reported that institutional review boards (IRBs) that oversee and approve medical experiments are under pressure to sanction risky research on those who cannot give informed consent and that it is unlikely that many who fully understand the risks would agree to participate without seeing a direct, personal medical benefit.

Leading psychiatrists and a high-ranking official at the state Psychiatric Institute in Manhattan, the state clearinghouse for drug research on kids and adults, have been lining their pockets with hefty drug-company speaking fees, consulting deals, board memberships, and subsidized international trips, state records show. Two members of the Psychiatric Institute in-house panel directly responsible for protecting the rights of mentally ill patients have financial ties to drug mega-firms like Eli Lilly, Glaxo Wellcome, and Bristol-Myers Squibb. The drug makers, while enriching the psychiatrists, are also picking up the tab for research at the Psychiatric Institute, where their products are tested for treatment of such ailments as depression,

hyperactivity, and schizophrenia. Drug-company-funded studies are often led by the same researchers who have private money deals with the firms. (Analyze This: Docs Get Drug Company $$ by Gregg Birnbaum and Douglas Montero, *The New York Post,* February 28, 1999.)

Zucker also cautioned that people from minority communities are especially vulnerable to becoming research subjects. In the infamous experiments conducted in New York, in which young boys were given doses of fenfluramine, a procedure without any potential therapeutic benefit, he notes that all of the subjects were either African Americans or Latino Americans.

The understaffed and underfunded federal Office of Protection from Research Risks (OPRR) at the U.S. Department of Health and Human Services investigates federally funded research programs involving human research subjects to ensure compliance with the Federal Policy for the Protection of Human Subjects (also known as the Common Rule). However, the Common Rule only applies to subjects in research regulated by the FDA and to subjects in research sponsored by some federal other agencies. Privately funded research is not covered by the Common Rule, so there are no protections for human beings who participate in this research.

Joseph Glazer, of the Mental Health Association in New York State, summarized discrimination against people labeled with psychiatric disabilities and violations of their civil liberties.

Having laws on the books that say people can't vote if they are mentally incompetent—or, in some states, "lunatics"—is discrimination. Having laws on the books that say a diagnosis of mental illness is sufficient grounds to take your children away in a family court proceeding is discrimination. Having laws sweeping across the country that say that it's okay to put violent sexual predators in state psychiatric hospitals with vulnerable people, who have in many cases already been victimized by such predators, is discrimination. (Joseph Glazer)

Glazer concluded that mental health advocates must fight discrimination everywhere they find it.

Ziegler testified graphically as to the way in which the lives of people labeled with psychiatric disabilities are devalued.

> *A friend of my family had a child with Prader-Willi syndrome [which causes an uncontrollable desire to eat] who was institutionalized. She was struck and killed by a car while crossing [a highway] in search of food. When I asked him how his damages action was progressing, he said it wasn't. He said all the lawyers had told him that her life had no value. That was the term the Nazis used to justify the killing of people with disabilities. It seems we have not come very far after all.* (Laura Ziegler)

Debbie Whittle testified to the power of perception and labels in defining the reality and experience of people labeled with psychiatric disabilities. She grew up in a family with two active alcoholics—a chaotic, unstable, unsafe environment that was marked by abuse and neglect. As a teenager, she experienced incest for several years and at age 17 left home, thinking she could just simply walk away and create a new life for herself. She did not realize, however, that the abuse and neglect had traumatized her so badly that she had disconnected from her own body, knowledge, wisdom, truth, and her capacity to self-heal.

> *There is a high correlation between trauma histories and the experience of being psychiatrically labeled. There are some common responses to trauma. It is common, when experiencing trauma, for a person to become numb, leave their body. Disassociate. It is incredible to me that these very coping strategies that kept folks alive are then called a disorder. It is absolutely amazing to me that our psyche has the ability to have us leave our bodies when our bodies are being tortured. That seems rather sane to me. Who would choose to stay in their body and experience that? And then, the first thing that happens when those folks show up for help is, they're called—they're told that they have disassociative disorder, instead of saying, "You have this wonderful capacity that has kept you sane and whole and alive." I would just like to suggest that we move away from a pathology-based mental health system that seems kind of like an oxymoron to me. I believe that the label of mental*

illness is the beginning of human rights violations. Healing is hard enough work without it being pathologized. (Debbie Whittle)

ADA has been of only limited benefit to people labeled with psychiatric disabilities. Although all people with disabilities have experienced some backlash as a result of ADA (which is viewed by some not as a civil rights law but as an entitlement law), in general, some progress has been made over the past few years. However, people labeled with psychiatric disabilities have seen little improvement. In fact, widely publicized reports of violent crimes by people labeled with psychiatric disabilities, although they are statistically rare, have precipitated stronger and more prevalent prejudice, which extends to the vast majority of people labeled with psychiatric disabilities who are nonviolent and law-abiding.

Negative stereotypes about people labeled with psychiatric disabilities are widely perpetuated by the media, which frequently seize on crimes involving people labeled with psychiatric disabilities and overreact. Unfortunately, such media reports harm and stigmatize the millions of other people labeled with psychiatric disabilities who do not commit crimes.

Because of a few dramatic episodes sometimes involving persons with a psychiatric diagnosis, all of us who have a diagnosis are made to face forfeiture of our civil liberties. (Joseph Walsh)

Patrick Smellie's research for his report on the news media's coverage of mental illness revealed crime reporters fall into the trap of ignorance in portraying suspects. *Feeding Stereotypes* was published in the March/April 1999 issue of *Quill*, the publication of the Society of Professional Journalists. Although Smellie found mainstream American news reports involving mental illness restrained compared with those in Australia and Britain, he cautions that he is not endorsing the American news media coverage.

Rather, it suggests something subtler: that the relentless framing of mental illness in the context of violence and criminality is amplifying, sustaining, and legitimizing a largely false picture of mental ill-health. (Mental Illness Coverage: Feeding Stereotypes by Patrick Smellie, *Quill*, March/April 1999.)

George Ebert of the Mental Patients Liberation Alliance in New York State echoed the opinions of most people who testified.

> *I would just like to offer our working platform. The first point is that we speak for ourselves. Next is, we seek an end to forced treatment of any kind. We seek full access to community support, advocates, and legal assistants in all involvement with the mental health system. We call for access to holistic alternatives to the medical model monopoly of mental health services. We seek an end to destructive psychiatric labels, and we demand accountability from the psychiatric system.* (George Ebert)

Public Policy Recommendations

Reinventing Social Security.

Simplify SSA disability regulations. SSA's redesign process should include uniform standards for SSI and SSDI program disability determinations, work incentives, and equitable earning amounts during trial work periods, regardless of program eligibility or disability.

SSA should provide ongoing training for its agency personnel, as well as beneficiaries and service providers, on available work incentive programs, including how to write a PASS plan.

Social Security establishes earnings limits for people with disabilities, except for people with visual impairments whose earnings limits are established by law, and at a much higher rate than for other people with disabilities. When federal law permits such discrimination, it is egregious.

Congress should enact legislation that makes earnings limits equal—regardless of disability.

HCFA should revise existing regulations to simplify the Medicaid waiver application process for states.

Many people indicate that a lack of affordable health care is a major disincentive to returning to work.

Federal law should be changed to allow continuation of Medicaid and Medicare coverage until equal or better health benefits—including voluntary mental health parity and prescription drug coverage—are available through an employer.

The Federal Government should ensure greater coordination at the federal, state, and local levels in the delivery of services to people labeled with psychiatric disabilities.

Congress should amend the FLSA and eliminate the provision for patient workers and other provisions that allow people with disabilities to work without compensation or at below the minimum wage.

DOL should revise applications for certificates of exemption and all other reporting documents to request such information as the number of hours each individual worked, number of people who worked, and the hourly wage paid to each person.

Without this information it is impossible to monitor these programs.

Information about successful model employment programs should be quickly disseminated and shared among agencies, task forces, committees, and others concerned with employment of people labeled with psychiatric disabilities.

In addition, Congress should fund additional demonstration projects that investigate employment of people labeled with psychiatric disabilities.

The Federal Government should strive to be the model employer of people with disabilities. Congress should investigate why the Federal Government has consistently failed to recruit, retain, and promote more people with disabilities.

This investigation should identify existing barriers and make recommendations on the employment and promotion of people with disabilities in all branches of the Federal Government, including Congress.

Federal forms should be screened to ensure that questions pertaining to psychiatric disabilities do not violate existing laws.

EEOC should penalize federal agencies that discriminate or fail to comply with existing provisions of all federal laws, including reporting requirements.

Congress should increase funding for EEOC and DOJ ADA-related training for employers and the judicial system.

ADA employment-related technical assistance and training for employers and also the judicial system are essential to ensure that people labeled with psychiatric disabilities are not discriminated against in the workplace or when they take employment cases to the court.

Human research subjects should be protected.

The National Animal Welfare Act of 1966 protects animals who are used in research, but no federal law extends those same rights to people who are decisionally incapacitated. In early 1999, the National Institute of Mental Health halted several research projects because they failed to give adequate protection to their human subjects.

Congress should enact strong federal laws that protect all human research subjects—especially people who are incapacitated and children—involved in federally as well as privately funded research. These laws should require, prior to participation in research programs, signed informed consent forms that are obtained without coercion and clearly state any possible adverse events that could result from participation in the research. The law should provide strict penalties for research facilities that fail to comply.

Protect the civil rights of people labeled with psychiatric disabilities.

Congressional hearings should be held on civil rights violations against people labeled with psychiatric disabilities.

Prosecute persons, institutions, or entities that violate due process, durable power of attorney, advance directives, and informed consent rights of people labeled with psychiatric disabilities.

Vigorous federal enforcement of civil rights laws such as ADA and other laws that protect the rights of people labeled with psychiatric disabilities is essential.

In addition, Congress should increase funding for federal technical assistance programs and to ensure enforcement of existing laws.

Congress should increase funding for protection and advocacy organizations to accommodate the increased workload.

Current funding levels do not adequately cover enforcement of laws that protect the civil rights of people with disabilities. With the elimination of state funding for prison legal service agencies, it is essential that P&A services are available to people labeled with psychiatric disabilities in correctional facilities. However, P&A organizations must be held accountable to their constituencies and meaningfully involve people labeled with psychiatric disabilities in programs and policymaking and as paid staff, including in management positions.

Establish local, accessible, 24-hour emergency assistance networks for people labeled with psychiatric disabilities.

Such networks could be operated using existing victim assistance programs that have trained staff and volunteers or that have significant numbers of people with a variety of disabilities on staff or as volunteers.

People labeled with psychiatric disabilities should not be denied their constitutional right to vote simply because of their disability or the type of facility in which they are receiving treatment.

Therefore, Congress should enact a federal law protecting the voting rights of people labeled with psychiatric disabilities.

Federal research and demonstration resources should place a higher priority on the development of culturally appropriate alternatives to the medical and biochemical approaches to treatment of people labeled with psychiatric disabilities, including self-help, peer support, and other consumer/survivor-driven alternatives to the traditional mental health system.

Currently, federal funding for psychiatric research is concentrated almost entirely on medical and biochemical approaches. Only a tiny fraction of research funding is directed toward programs of community support, and even less is directed toward peer support and other self-help approaches. This imbalance is only one of the reasons that such approaches receive less funding and are often funded only as time-limited demonstration projects, despite their considerable record of success and despite the fact that they tend to be favored by people labeled with psychiatric disabilities themselves.

Further, Congress should amend statutes regarding the review of grant applications for psychiatric research to ensure that people labeled with psychiatric disabilities are included in meaningful ways in the review process.

Employment and training and vocational rehabilitation programs must account for the wide range of abilities, skills, knowledge, and experience of people labeled with psychiatric disabilities by administering programs that are highly individualized and responsive to the abilities, preferences, and personal goals of program participants.

The successful components of employment demonstration programs should be implemented while identified weakness should be strengthened. Also, information about successful programs should be disseminated and shared among agencies, task forces, committees, and others concerned with employment of people labeled with psychiatric disabilities.

HCFA should revise existing regulations to make it easier for states to apply for Medicaid waivers under the Balanced Budget Act of 1997 for people with disabilities who return to work.

People labeled with psychiatric disabilities must be included in significant numbers in the planning, implementation, and evaluation of employment programs. It is essential that employment and training programs span the full range of employment options, rather than segregating people labeled with psychiatric disabilities in low-wage positions with few opportunities for advancement, or in segregated "make-work" programs.

Currently, many people labeled with psychiatric disabilities who already have advanced degrees or considerable high-level employment experience are actively discouraged from returning to their previous type and level of employment, and are shunted into programs far below their level of interest or skill.

In Conclusion

Americans with psychiatric disabilities believe—and this report confirms—that they are denied the self-determination necessary to control their own lives. Currently, politically and financially powerful forces oppose any consumer/survivor change to the existing mental health system. However, the system *must* change, and America must respond. Deprivation of human and civil rights cannot be tolerated in a country that was founded on the premise that everyone is created equal. The term "liberty and justice for all" must be underscored and applied for people labeled with psychiatric disabilities.

Glossary

ACT—assertive community treatment

ADA—Americans with Disabilities Act

CMHS—the Center for Mental Health Services is the bureau within SAMHSA that most directly deals with consumer-run services and programs

Consumer—a person who has used or still may be using mental health services, including medication, and who generally identifies her/himself with a diagnosis

CRIPA—Civil Rights of Institutionalized Persons Act of 1980

CSH—Corporation for Supportive Housing

DAI—Disability Advocates, Incorporated

DD Act—Developmental Disabilities Assistance and Bill of Rights Act of 1975

DMA—Division of Medical Assistance

DOJ—Department of Justice

DOL—Department of Labor

ECT—electroconvulsive therapy (shock treatment)

EEOC—Equal Employment Opportunity Commission

ERISA—Employment Retirement Income Security Act

FDA—Food and Drug Administration

FHAA—Fair Housing Amendments Act

FLSA—Fair Labor Standards Act

GAO—General Accounting Office

HAP—Homeless Assistance Programs

HCFA—Health Care Financing Administration

HOPA—Housing Opportunities for Persons with AIDS

HUD—Department of Housing and Urban Development

IDEA—Individuals with Disabilities Education Act

IEP—individualized education program

IOC—involuntary outpatient commitment, a legal process by which persons may be forced to accept treatment against their will in the community, most often through the use of medication

IRB—institutional review board

LRE—least restrictive environment

MCO—managed care organization

MHLAC—Mental Health Legal Advisors Committee

MHLS—Mental Hygiene Legal Services

MHPA—Mental Health Parity Act of 1996

NAMHC—National Advisory Mental Health Council

NAMI—National Alliance for the Mentally Ill

NCD—National Council on Disability

NEC—National Empowerment Center—a CMHS-funded technical assistance center, providing information and referral services to consumers and survivors

NIDRR—National Institute on Disability and Rehabilitation Research

NIMBY—not in my back yard

NIMH—National Institute of Mental Health, the institute within the National Institutes of Health charged with conducting research related to medical model treatments

NSH—Napa State Hospital

OPM—Office of Personnel Management

OPRR—Office of Protection from Research Risks

P&A—protection and advocacy

PAIMI—protection and advocacy for individuals with mental illness

Parity—equality

PASS—Plans for Achieving Self-Sufficiency

PERF—Police Executive Research Forum

PHA—public housing agency

RSA—Rehabilitation Services Administration

Restraint—a process in which patients are physically restrained with mechanical devices in order to make them immobile; some people include the use of drugs, terming this "chemical restraint"

SAMHSA—within the U.S. Department of Health and Human Services, the Substance Abuse and Mental Health Services Administration administers programs that deliver services, do

research or service delivery, support technical assistance programs for consumer-directed activities

SBH—severe behavior handicaps

SCHIP—State Children's Health Insurance Program

Seclusion—the removal of a person in a psychiatric facility to a private, generally locked, space, often without clothing, access to food, or access to bathroom facilities

SED—severe emotional disturbance

SMI—serious mental illness

SSI—Supplemental Security Income

SSDI—Social Security Disability Income

Survivor—a person who has experienced the mental health system and generally has negative experiences or impressions; psychiatric survivors believe they have not only survived their original emotional distress but also the "help" they received

TAC—Treatment Advocacy Center

VR—vocational rehabilitation

Appendix

Mission of the National Council on Disability

Overview and Purpose

NCD is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on

individuals with disabilities, access to health care, and policies that operate as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 USC 12101 et seq.).
- Advising the President, Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the Commissioner with respect to the policies and conduct of the Rehabilitation Services Administration.
- Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of NCD to promote the full integration, independence, and productivity of individuals with disabilities.

- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report.*

International

In 1995, NCD was designated by the Department of State to be the official contact point with the U.S. government for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became the Americans with Disabilities Act (ADA). NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.

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